International Perspectives on Social Policy, Administration, and Practice

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Knowledge, Innovation, and Impact

A Guide for the Engaged Health Researcher

AGEWELL

Springer

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AGE-WELL NCE Inc. (www.agewell-nce.ca) is Canada's Technology and Aging Network. The pan-Canadian network brings together researchers, older adults, caregivers, partner organizations, and future leaders to accelerate the delivery of technology-based solutions that make a meaningful difference in the lives of Canadians. AGE-WELL researchers are producing technologies, services, policies, and practices that improve quality of life for older adults and caregivers and generate social and economic benefits for Canada. AGE-WELL is funded through the Government of Canada's Networks of Centres of Excellence (NCE) program.

The STAR (Science and Technology for Aging Research) Institute (www.sfu.ca/starinstitute) at Simon Fraser University (SFU) is committed to supporting community-engaged research in the rapidly growing area of technology and aging. The Institute supports the development and implementation of technologies to address many of the health challenges encountered in old age, as well as addresses the social, commercial, and policy aspects of using and accessing technologies. STAR also supports the AGE-WELL Network.

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Sixsmith, Sixsmith, Mihailidis, Fang - Knowledge, Innovation, and Impact: A Guide for the Engaged Health Researcher

This book provides researchers with a straightforward and accessible guide for carrying out research that will help them to generate good science with real-world impact. All too often researchers excel at research design, data collection and analysis, but lack the knowledge and ability to commercialize or mobilize the outcomes of their research. Moreover, there is a lack of training and educational resources suitable to support researchers to navigate large, complex research teams composed of the wide range of disciplines and experience that are becoming typical. To improve the process of research into real-world impact, the book draws on the editors' experience of leading the AGE-WELL Network of Centres of Excellence and offers practical advice in three areas central to AGE-WELL (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life): transdisciplinary team working; co-creation approaches and methods; and, commercialization and knowledge mobilization. The format of the book is straightforward and emphasizes the practicalities of how to undertake the kinds of activities that researchers need to engage in if they are serious about achieving impact. There are concise chapters on key practical topics; worked examples; case studies; and associated learning activities. Written in plain language, this valuable resource will help guide researchers through the process of research-driven innovation.

Contents

Abbreviations

3D	Three dimensional
AGE-WELL	Aging Gracefully across Environments using Technology to Support Wellness and Long Life
AGE-WELL NCE	Aging gracefully across environments using technology to support wellness, engagement and long life Network of centres of excellence
AI	Appreciative inquiry
AI	Artificial intelligence
ANOVA	Analysis of variance
APPTA	Advancing policies and practices in technology and aging
ART	Antiretroviral therapy
AT	Assistive technology
CABHI	Centre for Aging and Brain Health Innovation
CAD	Computer-aided design
CAM	Computer-aided manufacturing
CARE	Case reports
C-ASAP	Community area silver alert program
CBPR	Community-based participatory research
CCBRT	Community Based Rehabilitation in Tanzania
CEAL	Challenging Environment Assessment Labs
CHEERS	Consolidated Health Economic Evaluation Reporting Standards
CIHI	Canadian Institute of Health Information
CIHR	Canadian Institutes of Health Research
CIPO	Canadian Intellectual Property Office
CLRI	Ontario Centres for Learning, Research and Innovation in Long-term Care
CMA	Canadian Medical Association
CONSORT	Consolidated Standards for the Reporting of Trials
COREQ	Consolidated criteria for reporting qualitative research
CoRSU	Comprehensive Rehabilitation Services Uganda

CRPD	United Nations' Convention on the Rights of Persons with Disabilities
CSA	Canadian Standards Association
CSPO	Cambodian School of Prosthetics and Orthotics
CTEF (Simon Fraser University)	Community Trust Endowment Fund
EMRs	Electronic medical records
EQUATOR	Enhancing the QUAlity and Transparency Of health Research
ERB	Ethical review boards
FNIGC	First Nations Information Governance Centre
GBP	British Pound Sterling
GDPR	General data protection regulations
HIV	Human immunodeficiency virus
HTA	Health Technology Assessment
ICTs	Information and communication technologies
IDRC	International Development Research Centre
IECs	Independent ethics committees
iKT	Integrated Knowledge Translation
IP	Intellectual property
IRBs	Institutional review boards
KITE	Knowledge, Innovation, Talent, Everywhere
KM	Knowledge mobilization
LBGTQ+	Lesbian, gay, bisexual, transgender, queer, and questioning
LIFE	Learning information for future empowerment
LMICs	Lower and middle income countries
LTBI	Latent tuberculosis infection
LTC	Long-term care
MAREP	Murray Alzheimer Research and Education Program
MHAC	Mental Health Awareness Club
mHealth	Mobile health
MHNA	Mental health needs assessment
MMA	Maximum achievable angle
MNDA	mutual nondisclosure agreement
MRI	Magnetic resonance imaging
MSFHR (I2C)	Michael Smith Foundation for Health Research (British Columbia)–Innovation to Commercialization program
NANA	Novel Assessment of Nutrition and Ageing
NASA	National Aeronautics and Space Administration
NASSS	Nonadoption, abandonment, scale-up, spread, and sustainability framework
NDA	Non-disclosure agreement

NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NPL	Natural language processing
NRC-IRAP	National Research Council Industrial Research Assistance Program
NSERC	National Sciences and Engineering Research Council of Canada
OARC	Ontario Association of Residents' Councils
OCAP	Ownership, Control, Access, and Possession
P&O	Prosthetics and orthotics
PCHT	Point of Care Healthcare Technologies project
PCT	Patent Cooperation Treaty
PIP	Product Innovation Pathway
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
PRISMA-P	Preferred reporting items for systematic review and meta-analysis protocols
QMU	Queen Margaret University
R&D	Research and development
RCTs	Randomized clinical trials
REBs	Research ethics boards
ROI	Return on investment
RQ+	Research Quality Plus
SA	Shareholders' agreement
SAFER	Shelter aid for elderly residents
SFU	Simon Fraser University
SH	Shareholders
SMART	Specific; measurable; attainable; relevant; timebound
SMS	Short message service
SPIRIT	Standard protocol items: recommendations for interventional trials
SQUIRE	Standards for QUality Improvement Reporting Excellence
SRQR	Standards for Reporting Qualitative Research
SSHRC	Social Sciences and Humanities Research Council of Canada
STAR	Science and Technology for Ageing Research (STAR) Institute (at Simon Fraser University)
STARD	Standards for Reporting Diagnostic accuracy studies
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TATCOT	Tanzania Training Centre for Orthopaedic Technologists
TCPS2	Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
TDW	Transdisciplinary working
ToR	Terms of reference
TRIPOD	Transparent reporting of a multivariable prediction model for individual prognosis or diagnosis
TRI-UHN	Toronto Rehabilitation Institute-University Health Network

TRI-UHN	Toronto Rehabilitation Institute-University Health Network
TRL	Technology Readiness Level
UHN	University Health Network
UK	United Kingdom
UML	Unified Modelling Language
UNBC	University of Northern British Columbia
USPTO	US Patent and Trademark Office
UW	University of Waterloo
UX	User experience
WHO	World Health Organization
WIPO	World IP Organization

Part I
Thinking About Impact

Chapter 1
Introduction: The Engaged Health Researcher—Why and How to Use This Book

Andrew Sixsmith, Judith Sixsmith, Alex Mihailidis, and Mei Lan Fang

Turning Ideas into Impact

The world of research has changed. The idea of an academic working alone in his or her ivory tower, isolated from the distractions of the outside world, is becoming a thing of the past. More and more, researchers are working in teams in large collaborative projects, where the funders have high expectations that the research will deliver tangible social and economic benefits. While impact is a worthwhile objective, achieving it in practice is a complex process, and many researchers are unprepared for the challenge of turning their ideas into real-world products, policies, practices, and services. How do you work effectively in a large team? How do you involve stakeholders and end users in your research? How do you *do* commercialization and knowledge mobilization? How do you manage relationships and expectations effectively with a range of different, nonacademic stakeholders? How do you reconcile these additional actions with your academic goals and activities? Researchers are increasingly expected to do more than traditional research tasks, but in our experience there has been limited practical support. The aim of this book is quite straightforward—to bring together current knowledge and experience to provide researchers with an accessible guide to how to carry out translational, *engaged* health research that will help to turn ideas, knowledge, and technologies

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into actions and outcomes that can have positive real-world impact on societies and economies.

Overview of the Book

The book is divided into four parts, starting by looking at the underlying ideas around engaged health research and then moving on to practical *how-to* chapters that constitute the main part of the book.

Part I: Thinking About Impact

This part introduces and discusses the underlying ideas and principles behind engaged health research—the why, what, and how of research-driven innovation. A major theme in this book is to plant the seed for us to start thinking about knowledge mobilization, innovation, and impact as being part of all stages of the research, even at the initial conceptual stages. The problem is how do we most effectively build these new activities into our research? For example, how do we work together with a diversity of external stakeholders to jointly conceptualize the problem area of our research? How should we co-design the project and what methods do we need to employ in knowledge mobilization or commercialization? How do we determine the expertise needed in the project? What do we mean by innovation and impact? How do we work toward impact as the goal? What are the barriers and opportunities? This part introduces the three ideas that we feel are crucial to an integrated, more holistic approach to knowledge mobilization: transdisciplinary working, co-production research, and effective outreach. Part I sets the scene for the rest of the book. The following three parts provide the practical *how-to* guides on key topics relating to the three pillars of engaged research.

Part II: Working Collaboratively

This part is about working collaboratively on the complex problems that exist within the health field. It is also about rethinking these problems and creating disruptive ideas and solutions. As well as breaking down the disciplinary silos that exist in academia, it requires researchers to work with stakeholders and communities in a meaningful way, as equal partners in the innovation process. The principle is fine, and there are many good articles that introduce the ideas behind transdisciplinarity and other forms of collaborative working, but what is less available are resources on how to do this effectively in practice. This part covers topics such as establishing the expertise base needed in the project; building authentic and meaningful partnerships; putting in place partnership mechanisms that support strong and enjoyable teamwork, introducing positive frameworks to support the integration of ideas across disciplines and sectors; working in ways which are inclusive of hard to reach or seldom heard groups; and minimizing the negative aspects of power relations within research. Issues of education and training are also covered, ensuring that the necessary social and teamworking skills are in place, thereby building capacity for future collaborative research. However, capacity building for the future is only part of the story for developing collaboratives frames for research. Developing a flourishing, person-oriented, and vibrant research culture is also necessary, a culture that is open to self-reflection and critical appraisal and most importantly is respectful of researchers and the participants in research.

Part III: Designing Together

This part focuses on research methods and is about involving stakeholders and end users as co-producers and co-creators of solutions. Researchers often have specialist knowledge and skills, for example, in the engineering or computer science fields, but if this expertise is to be applied successfully, solutions need to be grounded in the everyday knowledge and expertise of the person, the participant, the patient, or the customer. The key is to avoid the technology-driven approach by involving users at all stages from concept, through development and into real-world evaluation and implementation. This part covers topics such as how to conduct a robust and rigorous review of existing knowledge; co-create health innovations together with their intended recipients; meaningfully engage stakeholders throughout the entire research process; facilitate the development and maintenance of valuable relations between knowledge creators and knowledge users during the prototyping stage; and conduct ethical research, particularly when working with vulnerable groups. Aligned with the key messages and goals of this book, the topics addressed in this part enable to us to better identify, understand, and respond to the needs, aspirations, and everyday lives of those we aim to serve and co-produce practical solutions through health research innovation that can ultimately be turned into real-world products and services.

Part IV: Creating Research Products

This part focuses on the very practical aspects of turning ideas, prototypes, and new practices into real-world products and services. Typically, these have been seen as activities that come after the research phase, or “end of project knowledge translation.” This is the researcher’s get-out-of-jail card that allows him or her to quietly forget about impact and move on to their next project. We argue that these activities need to be brought forward into all stages of the research. For instance, thinking about commercialization or deployment right from the start will help to avoid building solutions that will inevitably fail. Visualizing what the final product might look like, who the customer is, and how much the product might cost are things that can be easily done, but have a big pay-off later on. This part covers topics such as how to effectively communicate with a wide audience, including other researchers, stakeholders, and partners; informing policy and influencing policy makers through research findings and appropriate methodologies, including how best to navigate the policy and health system landscapes; and, finally, topics around commercialization and knowledge mobilization, including important issues like dealing with intellectual property and integrated approaches to knowledge translation. All of these topics are meant to help researchers to work more closely with their teams, stakeholders, and partners in order to develop more effective solutions that will eventually be embedded in real-world contexts.

Each part has a brief introduction that gives the reader an overview about the ideas, themes, and connections they will find in the part and particular things that they might want to look out for.

How-to Chapters

The format of these how-to chapters is very simple and focuses on key topics, written in plain language that will help researchers through the process of research-driven innovation. The how-to chapters should help readers to visualize the kinds of non-core activities they need to engage in in order to ensure they progress toward innovation and impact. Each how-to chapter will address a key pillar in the translational research process. Each has a similar easy-to-follow format that will include the following sections:

The Challenge

Each how-to chapter addresses a specific topic or component in the translational research process: the issue, opportunity, or problem.

Key Ideas

The how-to chapters are short and to the point, and each provides an overview of 5–6 practical ideas relating to their particular challenge. It is helping the reader to start to answer the question: How do I go about X?

- What is the idea?

- What to do practical in terms of activities and outputs.
- May include a "box"—a very short case study or example to illustrate the idea.

Product Innovation Pathway (PIP) Model

This is an innovation in this book (more about this in Chap. 3). We want to help researchers to think about innovation at different stages of their project and not just something that is tacked on at the end. For example, researchers could be "doing commercialization" right at the start by carrying out an environmental scan of their market sector. However, commercialization activities further down the innovation pipeline will be very different. We have adapted and simplified the well-known TRL (technology readiness level) innovation scale into our own PIP model to make it more appropriate to the wide range of research projects. The model has five *stages*: innovative ideas; planning; development; testing; and outcomes. Every how-to chapter provides some pointers to the kinds of activities a researcher might have to engage in at various points in the PIP. These are guides and not blueprints, as every research project is likely to have its own objectives and dynamics that make it unique.

Finding Support

The book can only be an introduction to the complex world of translational research. It is important to provide readers with ideas for next steps and sources of further information: What should I do next? Who can I connect with to get help and support? Key resources, references and links to further reading.

Case Studies

Each of the how-to sections contains case studies that complement the how-to chapters in the book and will provide concrete examples to help the reader to visualize a key idea or approach in a very practical way: "…this is how we did it, and it worked really well…." The case studies will:

- Demonstrate how this example contributed to a successful translational research project.
- Provide examples of technologies and services at different stages of maturity.
- Illustrate major global health and healthcare challenges in the twenty-first century.

Learning Activities

As with case studies, the how-to chapters are supplemented by learning activities to reinforce learning about practical steps in a successful translational research project and relevant to a key health and healthcare challenge. The learning activities identify a key challenge and set out a particular problem, activity, and learning outcomes, as well as learning resources and any supporting materials needed in the activity.

The authors and editors of this book hope you find this book a helpful guide as we found it a rewarding experience putting it together with you in mind.

Chapter 2
Thinking Innovatively About Innovation Research

Andrew Sixsmith, Alex Mihailidis, Mei Lan Fang, and Judith Sixsmith

The Challenge: Innovation Is Complex

The title of this chapter highlights *innovation research*, rather than *innovation and research*. This is for two reasons. Firstly, we argue that research for its own sake is important, but having some kind of real-world benefit may also be an important objective. Improving our understanding of the way the world works is the goal of science, and using research knowledge to improve the lives and health of people is fundamental to the medical and health fields. However, turning research ideas into new products and services is often difficult. Excellent research may result in weak returns in terms of new enterprises, real-world products, and social and economic impact (Sixsmith, Mihailidis, & Simeonov, 2017).

Secondly, we suggest that "research" and "innovation" actually go hand in hand and we need to be smarter about the way we think about how they are connected. Sixsmith et al. (2017) argue that there may be an overly simplistic view of the innovation process in the research world. A recent report on fundamental science in Canada suggests that innovation is often seen as a straightforward linear process

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where "investments in basic and applied research should somehow cascade quickly into more goods and services along with healthier and happier populations" (Naylor Report, 2017, p. 63). However, innovation is a complex and often unpredictable process that doesn't lend itself to easy translation from research to real work applications. It is not just about developing new products or technologies because it is about thinking and doing things in new ways and implementing them as real-world solutions that will make a difference to individuals, society, and the economy. This is inevitably a messy process, where compartmentalizing the innovation process into discrete tasks and phases, such as basic research, solution development, and knowledge translation, is a flawed approach. Another flawed idea is that research results will naturally flow into implementation and adoption. The implication is that researchers need to be prepared to work in an iterative way, where the "flow" of the different parts of a project is interconnected and iterative, not necessarily in a linear direction.

The aim of this book is to shift our academic thought process toward thinking more actively about the innovation process within research contexts and to provide some practical approaches and tools that we hope will help people who work in the research community to take their ideas from "the lab into the real-world" or, more accurately, bring the world of research and the world of innovation closer together.

What Do We Mean by Innovation?

In getting to grips with the notion of innovation and impact, it is important to start defining some terms, for example, what do we mean when we talk about *innovation*? While there is no well-accepted definition, it could be said that innovation is about doing something in a new way that will have a positive benefit. Innovation might involve some kind of "invention," such as developing a new technology, but there are a few things to remember here. First, the invention itself is not the innovation because an innovation has to be implemented and used by people, businesses, etc. Second, innovation is not just about technology—it could be a process, service, policy, or a new business model. Third, innovation is a process and can look very different, depending on the context:

- Designing a new component in an existing product, system, or service may not require a huge investment or change. This *incremental innovation* is about small improvements that will make something more efficient, add value, reduce costs, etc. It might make an existing product more competitive or extend its shelf life in the market. Another approach is to apply expertise or solutions from one market or sector to another. While these may not look exciting, they typically account for most of the innovations that occur in business and services and can result in huge added value. They are also low risk, as they will be implemented and adopted within existing business processes. In the health sector, this could be a change to the way a service or procedure is organized and delivered that improves outcomes or reduces costs, but doesn't significantly impact on the organization as a whole. Even in areas such as pharmaceuticals, this low-key approach can be seen as crucial to innovation and contribute to the development of "blockbuster" drugs (Wertheimer & Santella, 2005, p. 4).

- *Radical innovation* is about creating new industries or markets and typically comes from an entirely new technology, service, or procedure. Obvious examples here are the telephone and the internal combustion engine that gave rise to the telecommunications and automotive industries in the twentieth century. The most radical innovation here was not necessarily the telephones and cars themselves but the communications networks and mass production that turned luxury products into mass-market products. Examples from the health sector include the improved sanitation and building of fever hospitals in the early twentieth century to control the spread of infectious diseases. These fever hospitals were in turn rendered redundant with the widespread introduction of vaccines and antibiotics in the mid-twentieth century. Taken together these radical innovations saw the eradication of many of the killer infectious diseases that were common throughout history.
- *Disruptive innovation* is about a new technology or process that significantly changes an existing market or process. These disruptive innovations often come from entrepreneurs or small businesses, rather than large businesses or established organizations (where existing investments and processes can produce inertia). Disruption is about effect and impact, such as creating a new market or changing the way people or an organization does something. An example of a disruptive innovation in the health sector is the implementation of laws banning smoking in public spaces and the positive impact that this has had on health outcomes and attitudes to smoking (Frazer et al., 2016).

Innovation as a Process

Innovation can also be a process that turns ideas into various tangible outputs that are then implemented and used. This concept is captured in the idea of the technology readiness level (TRL). The TRL defines the process of innovation as a series of stages of maturity from concept to implementation. We will talk about this further in Chap. 3 when we introduce the *Product Innovation Pathway* model that is used to organize many of the ideas and methods discussed in this book.

In any research project that aims to create a *product*, it is useful to think of *levels*: ideas-planning-development-testing-implementation. These levels have different requirements and dynamics. For example, *ideas* might be about defining a problem, establishing market need, or coming up with a range of potential solutions, while *testing* might require a trial of a new device or intervention. But importantly, this should be seen as an iterative process, where a project progresses in small, related actions similar to a learning process. Indeed, outcomes from one part of a project might require the research team to revisit previous actions. However, some of the things that we often see as part of a discrete phase of working might be a useful part of other phases of a project, e.g., thinking about markets and the implementation process could be something that is addressed even at early stages of a project.

Where Does Research Fit in the Innovation Process?

If we want research to result in innovation, then the research itself must be innovative in the way it is conducted. This is one of the key messages when we discuss the idea of integrated knowledge mobilization and transdisciplinarity in later chapters. We often think of researchers in the health sector as people who inhabit laboratories, focused on developing new drugs or technologies that might someday be used by patients and the public. But health research covers a very wide set of activities and disciplines, ranging from basic science through to more applied sciences (e.g., computing science and engineering), social sciences, policy, business, and the humanities. In the health sector, all these can be part of innovation in many different ways and at different points in the process, for example:

- Understanding the problems and needs of people and patients.
- Requirements analysis and modelling.
- Visualizing and developing solutions and prototypes.
- Designing and developing new solutions.
- Organizing trials and evaluating outcomes.
- Providing evidence of best practice or outcomes.
- Evaluating long-term impact.
- Understanding barriers to adoption.
- Developing delivery models.
- Understanding the business environment.
- Communicating results of research.
- Developing models of clinical practice.
- Translating research knowledge into practical services.

Looking at these, we can immediately see an issue—researchers will be required to work outside of their typical disciplinary boundaries. They may also often require working with professional or experiential stakeholders within research projects themselves. For example, a project to develop some kind of assistive technology may require different research and sectoral expertise, such as a psychologist and an occupational therapist working with engineers. Crossing disciplinary and professional sector boundaries to working together collaboratively is a key part of this book.

Failure to Launch

Herzlinger (2006) points out that government investment in health-related research and development is second only to defense spending in the United States, while private sector R&D spending is probably in the tens of billions of dollars. Despite all of the investment, hard work, and the need for new solutions, too many of these efforts fail to launch. This gap between R&D and real-world deployment has been labeled the "valley of death" (Hudson & Khazragui, 2013). A quick Google search of the expression "innovation valley of death" offers numerous possible reasons, including:

- Disjoint between academic processes and entrepreneurial processes.
- Failure to network outside the academic "comfort zone".
- Insufficient early-stage attention to the likely needs and decisions at a later stage.
- High cash demands versus low ability to raise it.
- Not enough emphasis on management, teams, and products.
- Assumption that pilots will naturally scale up to mainstream.

We often see impact case studies used to demonstrate where research has resulted in successful implementation and adoption of a new technology or process. These success stories are fine but are probably vastly outnumbered by unsuccessful ones that we tend to hear less about. Even where research leads to successful implementation, there is around a 17-year gap between getting research funding and when the results are put into practice in a real-world setting (Morris, Wooding, & Grant, 2011).

Box 2.1 A Personal Story

This is a fictionalized account but is typical of many projects that begin with good intentions but ultimately fail to deliver. The aim of the project was to develop a smart assistive environment to support people with cognitive impairments. The project was an international consortium of commercial, academic, and nonprofit partners and combined very significant public and private sector funding. Despite the investment, talent and hard work, a huge amount of research, and tech development, the project did not result in a product that could be eventually taken to market. Here are just some of the possible reasons:

- The initial project plan focused almost exclusively on technical aspects and technology development. Conversely, minimal resources and time had been earmarked for human aspects such as understanding user needs, working with them to develop prototypes, and then demonstrating and evaluating the solutions.
- The different aspects of the project were highly task-oriented and compartmentalized, making it difficult to communicate ideas and requirements between different teams.
- Motivations within the project varied greatly between different actors, often making it difficult to work in a cohesive way.
- Lack of knowledge around intellectual property and protection caused disagreement across partners on who owns what.
- The engineers and developers were too ambitious and unable to deliver key components, which undermined the viability of the overall system.
- The lack of a strong business case in the thinking around the system development.
- One of the major commercial partners pulled out due to changing priorities at management level.
- There were many different types of ethical challenges that created barriers for appropriate commercialization.

All large projects are going to face such challenges, but the key issue is that many of the problems encountered are not about the research or science but about aspects of the partnership such as organizational core values or changing personnel. Sixsmith et al. (2017) highlight a number of challenges to the research-into-innovation process. We will look at some of these and their implications.

Innovation in the Health Sector Is Particularly Challenging

While there is awareness that existing healthcare systems are increasingly unsustainable, there are many barriers to the sorts of innovations that might produce new ways to organize healthcare systems (Sebastianski et al. 2015). Indeed the healthcare sector could be seen as "innovation averse" (Herzlinger, 2006). A further dimension is that the problems and potential solutions are multifaceted and straddle different sectors. There are many of these so-called *wicked problems* (those complex, multilayered, and almost intransigent problems) within the health sector (Borger et al. 2017):

- Responding to the aging of populations.
- Obesity and unhealthy lifestyles.
- Inequalities in health.
- Pollution and ill health.

For example, the aging of populations is one of the most significant health challenges of the twenty-first century. Many of the authors in this book are part of the Canadian AGE-WELL Network of Centres of Excellence (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life NCE) that is actively developing technology-based solutions to help seniors and caregivers to live healthily and independently and age in place. AGE-WELL has identified a number of challenge areas for innovations that go beyond health and healthcare services and include issues such as financial wellness, supportive design of homes and communities, and social connectedness (AGE-WELL, 2019). All of these are connected in determining a person's ability to live independently in later life.

The take-home message is that all these are challenges that go beyond traditional academic boundaries or policy areas and require joined-up thinking and creative solutions if we are going to tackle them. We can think of a *challenge* as an important but complex and difficult problem area that demands innovation and deployment of real-world solutions. A *challenge* is not just about problems; it may be about economic opportunities and making a positive contribution to society, government policy, and the economy. A *challenge* is also much more than a research question:

- Result in significant social and economic benefits.
- Difficult to accomplish yet offer hope of being ultimately solvable.
- Demand collaboration across disciplines and sectors.
- Should capture popular imagination and political support.

Innovation is Both Social and Technological

When we think about innovation, we typically think about new technologies, devices, and systems—the hardware and software of new technology. But in reality, innovation is about how we organize the way we do things or how we reorganize ourselves in order to adopt some new device or system. Some examples are:

- Development and implementation of policies.
- Organization of service delivery.
- Clinical and professional practice.
- Business processes.
- Cultural, attitudinal, and behavioral change.
- Training and capacity building.
- Enhancing receptor capacity.
- Development or enhancement of new theory.

Any of these may indeed be based on some kind of new technology, i.e., technology-enabled, but that is not the only aspect. A second point is that successful innovation probably requires doing things on multiple fronts. For example, if a new health technology is to be implemented, this might require new processes to be devised, as well as policy changes to support the funding and communication and training to ensure adoption. We talk about this more in Chap. 3, where we describe the different types of "products" that a project might need to think about in order to ensure that new solutions are implemented.

Conclusion

Changing the Way We Do Research

The take-home message is that if we are going to make a difference, then as researchers, we need to do things differently. Researchers are often in an invidious situation, where they are increasingly expected to deliver tangible social and economic outcomes but often without the training, support, and resources needed to do this properly. Indeed, the "publish or perish" culture that persists within academia acts as a perverse incentive away from non-core activities, such as knowledge mobilization or community outreach. Despite this, there is a lot that researchers in academic institutions can do to make their work more impactful. A major goal of this book is to provide some practical ideas and tools that can help. The approach is very much about a democratization of research and innovation (von Hippel, 2005) that involves meaningful engagement with users and stakeholders. The wicked problems in the health sector are typically unique, requiring unique creative solutions that are built from the ground up *with*, rather than *for*, the people who will use and benefit from them. As mentioned in the Introduction, the three pillars of this approach are:

- Transdisciplinary working.
- Coproduction.
- Effective outreach.

We do not claim that this book will guarantee success in creating practical solutions and impact, but the aim is certainly to try to increase the likelihood of this happening.

References

AGE-WELL (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence). (2019). https://agewell-nce.ca/.

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., … Martin, S. (2017). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490.

Frazer, K., Callinan, J. E., McHugh, J., van Baarsel, S., Clarke, A., Doherty, K., & Kelleher, C. (2016). Legislative smoking bans for reducing harms from secondhand smoke exposure, smoking prevalence and tobacco consumption. *Cochrane Database of Systematic Reviews*, (2).

Herzlinger, R. E. (2006). Why innovation in health care is so hard. *Harvard Business Review*, May. https://hbr.org/2006/05/why-innovation-in-health-care-is-so-hard.

Hudson, J., & Khazragui, H. F. (2013). Into the valley of death: Research innovation. *Drug Discovery Today, 18*(13–14), 610–613. https://www.sciencedirect.com/science/article/pii/S1359644613000342.

Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: Understanding time lags in translational research. *Journal of the Royal Society of Medicine, 104*(12), 510–520. https://doi.org/10.1258/jrsm.2011.110180

Naylor Report. (2017). *Investing in Canada's future: Strengthening the foundations of Canadian research*. Ottawa: Advisory Panel for the Review of Federal Support for Fundamental Science. http://www.sciencereview.ca/eic/site/059.nsf/vwapj/ScienceReview_April2017-rv.pdf/$file/ScienceReview_April2017-rv.pdf.

Sebastianski, M., Juzwishin, D., Wolfaardt, U., Faulkner, G., Osiowy, K., Fenwick, P., & Ruptash, T. (2015). Innovation and commercialization in public health care systems: A review of challenges and opportunities in Canada. *Innovation and Entrepreneurship in Health, 2*, 69–80.

Sixsmith, A., Mihailidis, A., & Simeonov, D. (2017). Aging and technology: Taking the research into the real world. *Public Policy and Aging Report, 27*(2), 74–78.

Von Hippel, E. (2005). *Democratizing innovation*. Cambridge: MIT Press. https://web.mit.edu/evhippel/www/books/DI/DemocInn.pdf.

Wertheimer, A. I., & Santella, T. M. (2005). *Pharmacoevolution: The advantages of incremental innovation*. London: International Policy Network. https://www.who.int/intellectualproperty/submissions/Pharmacoevolution.pdf?ua=1.

Further Reading

For some excellent examples of healthcare innovation, see Morgan, B. (2019). Healthcare innovation—10 recent examples of powerful innovation in healthcare. Forbes.com. https://www.forbes.com/sites/blakemorgan/2019/03/12/healthcare-innovation-10-recent-examples-of-powerful-innovation-in-healthcare/#684d760757dc.

Chapter 3
Understanding the Product Innovation Pathway

Andrew Sixsmith, Judith Sixsmith, Mei Lan Fang, and Alex Mihailidis

In Chap. 1, we introduced the key idea of *engaged* research. In the later *how-to* sections of this book, we look at some of the practical actions we can take to implement these ideas in real-world research. Before we do that, we need to introduce two further organizing ideas that underpin this book:

- Products: The idea of research *products*—the technologies, services, toolkits, and policies that will be produced through our research and implemented and used in the "real world." Traditionally, the main outputs of academic research are ideas, concepts, theories, and empirical evidence that are disseminated in journal articles, books, and conference presentations. These are important but often fail to have a direct impact on potential beneficiaries. If we are to be serious about real-world innovation, the research outputs need to be *packaged* in a way that means they can be readily adopted by the people who will use them, i.e., the end users, patients, customers, and service providers.
- The Product Innovation Pathway (PIP) model: PIP represents different levels of product maturity—the process of moving from initial ideas toward deployment, mobilization, and adoption of a product.

These ideas are followed up in the *how-to* chapters, where we look at the different kinds of activities that a research team should be engaging at different stages in the innovation process.

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What Is a "Product"?

The first key idea is that research projects that aim to address social problems should produce tangible *products* that will have social and economic impact, that is, they should make a positive difference in people's lives. Progress toward these products can be defined and tracked across different levels of maturity as they move from basic research to implementation and deployment. It is important to make a distinction between research *outputs* and *products*. An output is anything created by a project during its research and innovation activities. These may include scientific papers, prototypes, patents, business plans, evaluation reports, etc. In contrast, a product is what the project is aiming to deliver as its ultimate end output that will be utilized in the real world. Products are tangible and require the research team to think in concrete terms:

- *What* does the product look like?
- *Who* is going to use it?
- *When/Where* is it going to be used?
- *How* is it going to get to its intended audience or market?
- *Why* would someone adopt and/or buy it (i.e., what is its value proposition)?

While this *productization* is typically addressed after the research phase in a project (if it is addressed at all), we propose that this process needs to begin right at the start of a project. For example, trying to visualize what the final product will look like will help research teams to identify the kinds of expertise needed to ensure the development of such products are an integrated part of the research process and to make decisions early on that will help to avoid problems that may be encountered later in the innovation process.

While the idea of innovation often implies new technologies, the *products* from research projects are typically wide ranging, for example:

- Technology products: These are the interventions, systems, and devices aimed at directly supporting the health of patients and consumers. Note that these may include new drugs or surgical procedures. They are, however, outside the scope of our book.
- Service products: These are the delivery models and mechanisms that will allow new technologies, solutions, etc. to be provided to the user or patient.
- Knowledge products: These are about the provision of information. They include policy briefs, guidelines, standards and regulations, models of good practice, as well as health-related information for the public.

Figure 3.1 provides a diagram of the Canadian AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence) definition of the outputs of its research projects. Innovation research works toward developing at least one of three products and, of course, a project may create several products that fit into one or more of the product types. Indeed, it might be crucial for a project to develop

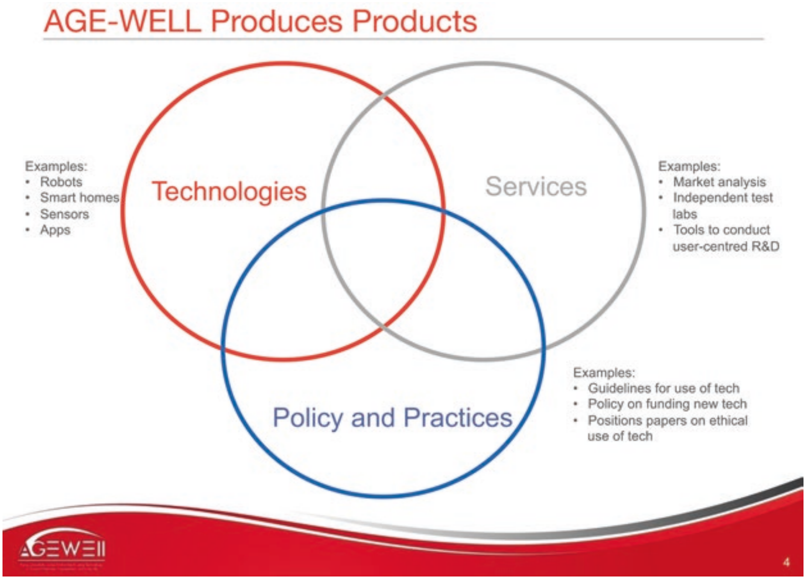

Fig. 3.1 Types of Products

multiple products in order to achieve real-world impacts. For example, if a technology is to be adopted, this may require the implementation of policy, provision of information to the users, or training on how to use or implement it.

While the idea of a product is intuitively connected to technologies, it is important that other types of products are defined in similar terms. Knowledge outputs from scientific research tend to be produced for academic audiences and so are quite inaccessible for use by lay audiences or product users, although the call for more accessible research products is becoming a more common requirement of research funders. Crucially, *products* need to be in a form that can be readily adopted by the people who will use them. However, researchers often have not developed the skills or the motivation to ensure that their products reach or are implemented by the intended user. The intention of this book is to support researchers in appreciating and developing these kinds of skills.

Visualizing Innovation: The Product Innovation Pathway (PIP)

The way products move from initial concept to final implementation is the second key idea in this chapter. This is particularly an issue to consider in relation to research and development of new technologies. Advancing innovation requires mechanisms that effectively manage and assess the risks of technology development through to its maturation into the market. There are a number of approaches available that serve this purpose. One approach to assess product maturation (i.e., usability, feasibility, and sustainability) that has become extensively used is the National Aeronautics and Space Administration's (NASA) *technology readiness levels (TRL)* (Mankins, 2009). The TRL scale encompasses nine levels of maturity with level one concerning the development of ideas and level nine indicative of technology in its most mature form (Fig. 3.2).

The use of TRL enables consistent, uniform mapping of maturity across different types of technology. The TRL approach has strong roots in the engineering field but is starting to be used elsewhere. For example, Canadian Institutes of Health Research (CIHR) use a simplified version of the TRL in their eHealth program (http://www.cihr-irsc.gc.ca/e/48614.html).

The TRL scale has been adapted in this book to create a more generic and inclusive Product Innovation Pathway model recognizing that there are a number of issues that make the TRL model less than ideal for use outside the field of engineering:

- The nine-point TRL model is primarily aimed at tracking and managing progress of a project as it has a high granularity that is important for evaluation but is less relevant to education and capacity building, where the aim is to increase insight and understanding and where a simpler model is more useful.
- There is quite a lot of overlap of different levels in the model in terms of actual activities that might be being carried out. For example, technology development might be a very iterative process in reality.
- TRL focuses on technology development and does not encompass other areas of project activity, such as commercialization activities.
- The TRL levels focus on technologies, and it is less appropriate for non-technology products such as services, policies, and practice. For example, TRL 4 "laboratory validation" is not appropriate for non-technology products.
- The TRL levels give the impression that innovation is a straightforward linear process, while the reality may be much more circuitous and reflexive, requiring

PIP Level	Description
TRL1	Basic principles and research data observed and reported.
TRL2	Technology concept and/or practical application formulated.
TRL3	Analytical and experimental proof of concept of critical function and/or characteristics.
TRL4	Validation of the technology in the laboratory.
TRL5	Validation of technology in a relevant environment.
TRL6	Demonstration of technology in relevant environment.
TRL7	Technology prototype demonstrated in an operating environment.
TRL8	Technology system completed and qualified through test and demonstration.
TRL9	Technology system in its final form ready for full (commercial) deployment.

Fig. 3.2 Technology readiness levels (general definitions)

a more iterative process. This means that in the PIP model, end results should be evaluated by attainments that, for example, benefit end users and the wider community, which influence policy and quality of life rather than defining "success" only by financial gains.

The Product Innovation Pathway Model

In this book, we argue that the innovation process across different product types is broadly similar, and we have adapted the different technology readiness levels to create a simpler and more inclusive model of health innovation and product maturity. We have called this the Product Innovation Pathway (PIP) model (Table 3.1). There could be many ways of representing the PIP. Our model is meant to be simple and generalizable across different types of research projects and products. The key aim of this book is to provide a consistent and simple framework that will be used in all the following *how-to* chapters.

- Level 1: Innovative ideas. All research projects and potential products have to start with ideas. A major theme in this book is that researcher or technology-driven solutions are likely to fail and that co-creation and collaborative approaches are more likely to result in something that is useful. To start with, this could be a problem or a need that someone has identified such as a service provider who wants to make her or his services more accessible to patients or users. It could be an idea that is based on some new discovery that has been made in a lab. It could be the application of some well-established idea from one sector to another, such as everyday technologies that have trickled down from space program research.
- Level 2: Planning. Rather than *incubation*, which seems to point to a hot housing of ideas and research activity by researchers themselves, and separated from real-world contexts, the new title of *planning* refers to a much broader process or set of activities that can include input from a range of nonacademic stakeholders. For example, the research and development of technologies to improve the health and well-being of older adults might involve healthcare professionals, industrial partners, older adults, and carers that locate the research firmly in the everyday contexts in which the technologies will be used. As such, rather than incubation with its implication of separation and spontaneous growth, the notion of planning is very much seen as an iterative, inclusive, and participatory process.

Table 3.1 Product Innovation Pathway levels (general definitions)

PIP level	Description
PIP1	Generating innovative ideas
PIP2	Planning the project
PIP3	Developing the product
PIP4	Testing in real-world settings
PIP5	Creating outcomes and impact

- Level 3: Development. A key step in this process is the development of the tangible product itself. This may include prototypes of a specific technology, such as robot or sensor, of drafts of new practices, policies, and guidelines. The approaches used in the development phase will differ based on the type of product being developed (and is outside of the scope of this book), but the common feature is that product development is an iterative process that involves the development of multiple prototypes, drafts, etc. This iterative development process should be driven by constant input and feedback from key stakeholders, such as end users of the intended product.
- Level 4: Testing in real-world settings. New ideas, models, findings, and prototypes need to be tried out in real-world settings—in situations that approach the real-world context in which it is going to be used. In some areas, this kind of testing has very rigorous and well-established protocols. For example, in the development of new drugs, these have to be tested in randomized, clinical trials with real patients to determine the efficacy and potential side effects. In other types of research, this kind of testing is not always feasible. For example, buildings cannot usually be tested prior to their construction, so post-occupancy evaluation is used to provide information for future projects. Complex interventions such as new technologies or services are typically piloted with potential end users, but often the scale of the research is limited by practical considerations. However, the key objective here is to provide strong evidence about that usability, feasibility, and sustainability of a product. This will provide essential information about how the product needs to be adapted or commercialized. Evidence from trials and product testing will help to convince potential users and consumers to adopt or purchase the product.
- Level 5: Outcomes and impact. Research needs to go beyond the normal academic boundaries in order to ensure real-world impact. The *products* of a project—a technology, policy, and/or practice or service—need to get into the hands of the people or groups who will benefit from them. It is not enough to assume that good ideas will be automatically adopted. Typically, these *knowledge translation* activities are put at the end of a project. In this book, we argue that this needs to be at all levels of the PIP model. However, it is clear that many of the practical and commercial steps required to get products adopted will occur at this stage.

These different levels constitute an important organizing idea that recurs in many of the chapters in this book. Specifically, the book's *how-to* chapters provide examples and suggestions about the kinds of activities a project might engage in at different levels in the model. These are not meant as a set of blueprints but are offered as suggestions and examples of the kinds of activities that might be needed at different steps in a project.

Progressing Through the PIP Levels

It is very important that the PIP model is viewed as a framework rather than a simple linear set of steps through which a project progresses. Innovation is rarely straightforward, and there could be many different pathways through the innovation process:

- The pace and direction of movement through the different levels will vary from project to project, depending on factors such as technical challenges.
- Progress is nonlinear, and iterative projects work toward implementation, but this might not always be in one direction.
- These are levels and not stages: this isn't a blueprint, and project teams need to work creatively to progress.

However, a key point is that all projects have a start, a middle, and an end. In particular, the end point that we emphasize in this book concerns the production of a product placed in the hands of people who will benefit from it. It is this *end point* that the current book is aimed at, i.e., helping researchers to better visualize and plan toward delivering their product to people who need it.

Many of the activities that are typically thought of as happening in an end phase of knowledge translation or commercialization need to be thought about much earlier in a project if they are to have more chance of success down the line. The *how-to* chapters in this book deal with different project activities to help research achieve direct social and/or economic impacts. Accordingly, each of these chapters contain guidelines that show the sorts of activities researchers might consider carrying out at the different PIP levels to create products that have tangible benefits.

Key Messages

- Projects are expected to create one or more tangible real-world products.
- Products can be of three main types: technologies, policies and practice, and services.
- Product innovation is characterized by five levels of maturity from early ideas to real-world implementation.
- Projects can progress though these levels in different ways—we call this the Product Innovation Pathway model.
- Later chapters in this book look at the different kinds of project activities at different levels in the PIP model.

Reference

Mankins, J. C. (2009). Technology readiness levels: A retrospective. *Acta Astronautica, 65*(9–10), 1216–1223. http://www.onethesis.com/wp-content/uploads/2016/11/1-s2.0-S0094576509002008-main.pdf.

Chapter 4
An Introduction to Transdisciplinary Working

Alisa Grigorovich, Pia Kontos, Judith Sixsmith, Mei Lan Fang, and Mineko Wada

The Challenge

Transdisciplinary working (TDW) is a new model of knowledge production that has emerged in response to a changing research environment in the late twentieth century. In particular, researchers are increasingly required to be accountable and responsive to social priorities and needs, and there is greater pressure to bridge their research with real life (e.g., bench to bedside, discovery to commercialization). This has prompted researchers and funders to adopt new types of approaches to knowledge production that are context-driven, problem-focused, and participatory. These approaches involve the collaboration of multiple academics across scientific disciplines and experiential non-academics across sectors (e.g., industry, patients, policymakers, health professionals). This is typically practiced in large-scale research and training initiatives where the purpose is to advance knowledge and create innovative solutions (Stokols, Hall, & Voge, 2013). Integration and innovation at this scale are difficult and require TDW to ensure the *problem space* and research processes and outcomes are not restricted by a single disciplinary and/or sectoral framing. TDW is thus most appropriate for the most complex and seemingly stubborn (often referred

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to as *wicked*) social problems, which necessitate not one but often multiple solutions (Boger et al., 2017). Solving wicked problems cannot be done by refining or adapting existing disciplinary or sector-specific knowledge, but rather it requires transcending current ways of thinking and progressing toward more holistic solutions. TDW supports the creation of a *transformative space*, that is, a *rethinking* of the problem area by linking diverse types of knowledge and actions, and envisioning how to mobilize resources and create new possibilities for social change (Marshall, Dolley, & Priya, 2018).

Given the scale and complexity of health and healthcare-related issues, TDW is particularly useful for the development of innovative solutions that can have real-world impact. For example, TDW can enable the development of technologies to assist older adults to live well in later life (Boger et al., 2017; Sixsmith, 2013; Wada et al., 2020). Achieving such impact requires the engagement of diverse stakeholders in the research and development process (e.g., academia, industry, government, and everyday citizens). Supporting active collaboration between these stakeholders ensures that research and development are driven by the necessary experiential and scientific expertise (Boger et al., 2017; Sixsmith, 2013). Despite the potential of TDW to improve the development and commercialization of new solutions, it has yet to be systematically adopted. This is largely attributed to the lack of knowledge or exposure to TDW, as well as habitual ways of working within academic research settings. In particular, academic research value systems continue to reward individual research accomplishments and favor single-discipline, investigator-initiated, and academic-based research. This is compounded by the use of traditional academic knowledge dissemination strategies (e.g., peer-reviewed academic journals, scientific conference presentations), which often fail to reach large segments of the general public. The purpose of this chapter is to introduce health researchers to principles of TDW (with brief examples), its benefits, and some ideas regarding how to evaluate it. In doing so, we hope to support research efforts that more comprehensively address complex social problems in ways that make a positive difference to health and well-being.

Key Ideas

What Is TDW, What Are Its Benefits, and How Is It Evaluated?

TDW involves academics from diverse scientific disciplines collaborating with non-academic stakeholders (e.g., older adults and caregivers, industry and financers, policy-makers) as research partners. Regardless of the nature of their partnership, a defining principle of TDW is to engage stakeholders in all aspects of the research process rather than restrict their role to passive test subjects who only provide test-design feedback (Grigorovich, Fang, Sixsmith, & Kontos, 2019). Another defining principle of TDW is the integration of knowledge across scientific disciplines and between academic and non-academic sectors (Grigorovich et al., 2019). TDW has been shown to have multiple benefits, for individuals (e.g., researchers, trainees) and for society. Given the longitudinal and complex nature of TDW research, it is key that its impact and quality are evaluated using a multidimensional approach that considers not only research outcomes but also the process of conducting the research.

Engaging All Stakeholders as Equal Partners

Given the importance of *crossing disciplinary and sectoral boundaries* and ensuring that projects are *driven by real-world needs*, a cornerstone of TDW is the development of equitable partnerships between academics and non-academics. More specifically, by equitable partnerships, we are referring to a collaboration built on mutual trust and respect, *common understanding of the problem*, equitable access to knowledge, and equitable access to decision-making powers. This, in turn, facilitates *shared goal creation* between academics and non-academics. Equitable partnerships challenge the supremacy of expert (e.g., scientific and/or academic) knowledge in research by actively exchanging, incorporating, and valuing diverse perspectives of all stakeholders involved (Dupuis et al., 2012).

Challenging and addressing asymmetries in knowledge and decision-making are crucial for ensuring equitable partnerships in practice. Academics are often considered to be the *experts* within research communities and are typically key decision-makers based on their recognized social status and the prestige accorded to scientific and professional expertise. To ensure that non-academics feel valued and are able to participate fully in the research process, it is required that academics share power and reflect on how they may intentionally (or unintentionally) silence the voices of non-academics in the research. This will require the development of new skills and expertise for both non-academics and academics. For non-academics, this may involve education about the process of research, including its methods and techniques. For academics, training is needed on how to recruit and engage non-academics, how to adapt scientific communication strategies to individuals without technical expertise, and how to offer opportunities for non-academics to participate in research that builds on their skills, talents, and knowledge. Finally, developing equitable partnerships requires a substantial investment of time and the provision of opportunities that allows all stakeholders to learn from one another, engage in mutual dialogue about the research problem, and *share in goal creation* (e.g., collaboratively developing the project goals, visions, and plans).

Transcending Boundaries and Creating Shared and New Knowledge

Addressing *wicked*, *needs-driven*, and *real-world problems* requires that knowledge be integrated across diverse disciplines and academic and non-academic sectors. Each discipline and/or sector in its distinct approach values some aspect of the research problem and a particular set of specialized tools or strategies for understanding it (e.g., methods, theories). Development of holistic solutions thus requires integrating different understandings of the *problem* across disciplines and sectors to more effectively *understand the complexity of wicked problems*. Integration in the context of TDW includes the identification and merging of knowledge about the problem across disciplines and sectors, identification of gaps in understanding, and the use of diverse tools and strategies to address these gaps. The ultimate purpose of this process is to develop a comprehensive picture of the problem so that solutions can be created. At a minimum, this requires that the research project is not defined by a single disciplinary and/or sectoral framework and that a range of perspectives, ideas, and methods are engaged in the research process. However, integration is not merely learning about the results of work in other disciplines and/or sectors (e.g., passive contribution) but rather requires a collaborative rethinking of the problem area through the sharing of knowledge, building a *common understanding* of the problem, and developing holistic solutions. Integration of knowledge thus requires going beyond combining different types of academic knowledge and ideas (i.e., interdisciplinarity) that do not challenge or change disciplinary assumptions, as well as the *integration* of knowledge across academic and non-academic sectors.

To achieve successful integration, all research stakeholders must jointly discuss information drawn from their own expertise, develop a shared vision of the problem area, and *create a set of shared goals for the research*. It is important to foster interaction and knowledge exchange among stakeholders by engaging them in the generation, interpretation, and exchange of knowledge. Arts-based methods are particularly useful in this regard as they enable stakeholders with different ways of relating/organizing/understanding information to share different, and often conflicting, perspectives and to come to a *common understanding*. Working together to integrate knowledge begins with collaborative group discussions to identify core concepts and terms across disciplines and sectors (as well as their meanings) followed by conceptual work to link terms and concepts through the development of a joint vocabulary and joint models. TDW emphasizes that integration is an ongoing process throughout the research and that every phase of the research may involve iterative adjustments to the objectives or the definition of the research problem and its solutions to accommodate new knowledge gained. See Box 4.1 for an example of this principle.

Box 4.1 Example of Integration of Knowledge

In a project concerned with the creation of a research-based drama to challenge stigma associated with dementia, a 1-day arts-based workshop was held (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016). This workshop included persons living with dementia and their family members, visual and performance artists, and academic researchers from nursing, leisure studies, and public health. The purpose of the workshop was to explore the meaning and impact of stigma on persons living with dementia and their families, their experiences of life with dementia, and how they challenge (or would like to challenge) the dominant tragedy discourse associated with dementia. The workshop included two separate audio- and video-recorded focus groups with persons living with dementia and family members, facilitated by the researchers in the morning. In the afternoon small groups were formed wherein persons living with dementia and their family members worked with a visual and performance artist and one of the researchers to co-create an artistic representation of what they wanted to highlight from the morning focus group discussion. At the end of the day, the groups came together, and each shared their visual representation and its meaning. This participatory process and the use of arts-based methods created a space where multiple and diverse understandings could be explored and new data could be generated and shared. The significance of this is that the process of mutual storying fostered a *common understanding of the problem* and generated more promising solutions for change (e.g., ways of collectively challenging stigma).

Making a Positive Difference with TDW

Recent research on TDW in practice (e.g., Grigorovich et al., 2019) suggests that taking a TDW approach enables people to think outside of the box and collectively come up with new ideas to solve problems that are broadly considered to be very complex and difficult to solve. Further, it improves the social relevance of research as it supports public involvement and increases the exposure of new ideas in journals and practitioner forums. Importantly, TDW also improves research productivity and funding success, and enriches the learning and training experiences of novice researchers. For example, TDW was found to benefit trainees and early career researchers in that it increased mentorship opportunities and advanced their career trajectories. It was also found to be associated with a greater number of academic outputs (e.g., number of peer-reviewed publications, scientific presentations, proposals submitted, and funded grants received) and cross-institutional collaborations, which supported international competitiveness. In this way, TDW can help researchers to progress in their careers.

In terms of making a positive difference in the real world, using a TDW approach provides opportunities for new ideas to be taken up by policy-makers, professionals in health and social care organizations, and the general public. For example, adoption of a TDW approach can help to progress the adoption of technological products and services through consistent, public involvement. Researcher-dominated projects run the risk of producing technologies that fail to progress beyond the prototype stage because of a poor fit between the technology and the people it is intended to serve. The involvement of a wide range of stakeholders in TDW research increases the chances of producing technologies which are not only fit for purpose but also improve people's everyday lives. TDW is important, therefore, because it has the potential to produce knowledge and technologies that improve the lives of individuals and communities, including those of academics themselves and of the experiential stakeholders who work with them.

Determining the Impact of TDW

Evaluating TDW outcomes is often difficult in the initial phases of the research. In the earlier phases of the research, it is thus important to identify and evaluate working practices that support future success and social impact, and assess these at the individual, project, or organizational level. These can be considered as the basic building blocks that need to be in place to allow for TDW (e.g., inclusion of multiple methods and/or theories, disciplines, and sectors, inclusion of non-academic stakeholders as full research partners). Longitudinal evaluation of TDW outcomes and processes should include both traditional academic markers of scientific excellence (e.g., academic publications, presentations, grants) and markers of societal or extra-scientific impact (e.g., changes in health outcomes, market adoption of technologies, changes in policy and/or practice). It should also demonstrate that the outcomes have come from a dialogue between science and society (i.e., between researchers and/or scientists and everyday citizens). Multiple methods can be used to evaluate TDW outcomes and processes including qualitative methods (e.g., interviews, focus groups, document review) to explore stakeholders' perspectives on their experiences, and quantitative methods (e.g., survey, bibliometrics, network analysis) to capture the number and diversity of outcomes and interactions between stakeholders (e.g., within and across sectors or disciplines). An example of this type of holistic evaluation approach is the Research Quality Plus (RQ+) framework, developed by Canada's International Development Research Centre to ensure that locally grounded and globally relevant research is equitably evaluated and rewarded (Ofir, Schwandt, Duggan, & McLean, 2016). The RQ+ is a systematic approach to evaluation that is particularly relevant to TDW because it considers research in context, adopts a multidimensional view of quality, and values both qualitative and quantitative empirical evidence.

Summary

This chapter has introduced the concept of TDW, including two key principles of TDW, its benefits, and some ideas regarding how to evaluate its quality and impact. Further development of *how to do* TDW, case studies of implementing TDW, and some learning activities can be found in the Communications section of this book (Part IV).

Learning More

- See other chapters in this book: Building partnerships and co-creating with diverse stakeholders (Chaps. 6, 13, 15); Working together as a transdisciplinary team (Chap. 9); and Addressing real-world problems through transdisciplinary working (Chap. 17).
- AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence) (2017). CC3 transdisciplinary working: a resource for transdisciplinary working in aging and technology. http://agewell-nce.ca/wp-content/uploads/2017/09/CC3_Best_Practice_onepager_-Oct11_2017_FINAL.pdf.
- CC3 transdisciplinary working. (2017). *Transdisciplinarity Game Night.* AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence). https://www.youtube.com/watch?v=yoB089qSs0I animation.
- Grigorovich, A., Fang, M. L., Sixsmith, J., & Kontos, P. (2019). Defining and evaluating the effectiveness of transdisciplinary research in aging and technology. *Disability and Rehabilitation: Assistive Technology, 14*(6), 533–542.
- Ofir, Z., Schwandt, T., Duggan, C., & McLean, R. (2016). Research quality plus [RQ+]: a holistic approach to evaluating research. Ottawa: IDRC. https://www.idrc.ca/sites/default/files/sp/Documents%20EN/Research-Quality-Plus-A-Holistic-Approach-to-Evaluating-Research.pdf.

Key Messages

In response to the rising demand for research to be more accountable and responsive to societal priorities and needs, TDW has emerged as an approach that has enormous potential to support the development of solutions to complex social problems:

- Two defining principles of TDW are *building equal partnerships* with a range of stakeholders and the *integration of knowledge* across academic and non-academic sectors.
- Adoption of TDW has benefits for individuals, for organizations, and for society.
- Evaluating the quality of TDW research requires a comprehensive and longitudinal approach.

References

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., Mihailidis, A., … Martin, S. (2017). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490. https://doi.org/10.3109/17483107.2016.1151953

Dupuis, S., Kontos, P., Mitchell, G., Jonas-Simpson, C., & Gray, J. (2016). Re-claiming citizenship through the arts. *Dementia: The International Journal of Social Research and Practice, 15*(3), 358–380.

Dupuis, S., Whyte, C., Carson, J., Genoe, R., Meshino, L., & Sadler, L. (2012). Just dance with me: An authentic partnership approach to understanding leisure in the dementia context. *World Leisure Journal, 54*(3), 240–254.

Grigorovich, A., Fang, M. L., Sixsmith, J., & Kontos, P. (2019). Defining and evaluating transdisciplinary research: Implications for aging and technology. *Disability and Rehabilitation: Assistive Technology, 14*(6), 533–542. https://doi.org/10.1080/17483107.2018.1496361

Marshall, F., Dolley, J., & Priya, R. (2018). Transdisciplinary research as transformative space making for sustainability: Enhancing proper transformative agency in periurban contexts. *Ecology and Society, 23*(3), 8. www.ecologyandsociety.org/vol23/iss3/art8/#transformative.

Ofir, Z., Schwandt, T., Duggan, C., & McLean, R. (2016). *Research quality plus [RQ+]: A holistic approach to evaluating research*. Ottawa: IDRC. https://www.idrc.ca/sites/default/files/sp/Documents%20EN/Research-Quality-Plus-A-Holistic-Approach-to-Evaluating-Research.pdf.

Sixsmith, A. (2013). Technology and the challenge of aging. In A. Sixsmith & G. Gutman (Eds.), *Technologies for active aging* (pp. 7–25). New York: Springer.

Stokols, D., Hall, K. L., & Voge, A. L. (2013). Transdisciplinary public health: Definitions, core characteristics, and strategies for success. In D. Haire-Joshu & T. McBride (Eds.), *Transdisciplinary public health: Research, methods, and practice* (pp. 3–30). San Francisco: Jossey-Bass.

Wada, M., Grigorovich, A., Fang, M. L., Sixsmith, J., & Kontos, P. (2020, January). An exploration of experiences of transdisciplinary research in aging and technology. In Forum Qualitative Sozialforschung/Forum: Qualitative Social Research (Vol. 21, No. 1). https://doi.org/10.17169/fqs-21.1.3332.

Chapter 5
Knowledge Mobilization for an Engaged Researcher

Igor Gontcharov, Karen Kobayashi, and Amanda Grenier

The Challenge

In this chapter, we offer several ideas about how an *engaged researcher* might become involved in the process of *knowledge mobilization*. But where does this new knowledge mobilization imperative come from? And what does it mean to extend beyond the former expectations of *knowledge translation* and *impact plans* to actively participate in collaborative practices of *knowledge production* and/or *knowledge co-creation*?

To answer these questions, we take a brief look at how our understanding of knowledge production has changed over the past two decades. We will highlight the background ideas that shape knowledge production and the relationship(s) between academia and society and point out the contextual factors within which engaged researchers must work if they are to be successful in advancing knowledge and practices for older adults. The underlying idea is that regardless of the particular methodology taken or level of *knowledge* of *co-production and sharing*, the process by which engaged researchers carry out their work should be both *critical* and *reflexive*.

The centrality of *research* and *training* in the mission of academic institutions was commonplace throughout the twentieth century and continues to date. The expectation that academic institutions should consider and demonstrate *societal*

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impact, however, only became prominent throughout the 1990s and early 2000s (see Van den Akker & Spaapen, 2017, for an overview of the concept of societal impact). The ideas that characterized this shift were that the research and training mission of any academic institution should have a degree of social validity, which contributes directly to understanding and providing solutions to the challenges brought about by *globalization* and the 'risk society.'

Since the early 2010s, the idea of impact in research and training, and the very relationship between *science and society*, is increasingly understood to require critical reexamination and restructuring. The emergence of *knowledge mobilization as a concept* most clearly marks this shift to impact, and movement from earlier initiatives focused on *knowledge exchange/translation/transfer*, *implementation science*, and/or other approaches such as science communication and knowledge management.

The challenge is therefore not just about integrating the new imperative of societal impact but about integrating it while simultaneously revising 'old' *paradigms* and ways of thinking about the relationship between science and society. Such revision requires an awareness of the broader social and global contexts within which knowledge is mobilized and shared, as well as knowledge of the ways of empowering society in the processes of knowledge production.

This is a double challenge for researchers and universities, since there are still many unresolved tensions between the roles of researcher and educator, funding requirements, and what counts as knowledge and impact. Further, the concept of impact is subject to multiple agendas. Therefore, the pressure to achieve societal impact must also be understood within shifting dynamics such as the relationship between public and private services and/or industry partnerships, changing global markets, and the expectation that universities serve as training grounds for a *highly competitive*, *flexible*, *and multidisciplinary labor force*.

In the following section, we outline *four key ideas* that the engaged researcher can consider when setting out to practice knowledge mobilization:

- Key idea 1—Knowledge mobilization is not merely knowledge transfer.
- Key idea 2—Knowledge practices must extend beyond 'twentieth-century models of science.'
- Key idea 3—The importance of developing a *culture* of knowledge mobilization.
- Key idea 4—Research impact begins with changes in the academic context.

Key Ideas

Knowledge Mobilization Is Not Merely Knowledge Transfer

The traditional view of *knowledge transfer or translation* is about communicating a message from academia to other fields of research, sectors of the economy, policy makers, and the public. Knowledge mobilization differs substantially from this idea of knowledge transfer and other concepts such as *implementation science*, *knowledge translation*, and *science communication*, since it seeks to reimagine the very relationship between science and society.

A manual written on knowledge transfer just 10 years ago would have outlined the need to identify stakeholders and find a way to package new data into a suitable format to achieve impact. Usually, the task would have involved the development of a *knowledge transfer plan* or an *impact plan*. In the present day, this would not be sufficient, given twenty-first-century ideals and expectations of *engaged*, *responsible*, and *responsive* research. However, this transition is not without challenges. Former patterns of knowledge production are deeply entrenched and supported by other social institutions, such as academic hiring, tenure, and promotion, and academic systems are slow (and perhaps hesitant) to adapt these new modes of practice.

The idea of *knowledge transfer* emerged when science was conceptualized as theoretical and applied, and was structurally distinguished, and even insulated from other sectors of society. When policy makers identified the gap between discovery and implementation as a social problem, the proposed solution was to close the gap by intensifying academic knowledge translation and transfer from one sector to another, thereby facilitating its uptake and implementation in day-to-day products and services.

The concept of knowledge mobilization thus emerged as a critical response to the overall ineffectiveness of the knowledge transfer paradigm in closing the gap between discovery and implementation. However, 30 years later, the gap is still there. While individual success stories of new and helpful practices and products exist, the general gap between discovery and implementation has neither been closed nor significantly shortened.

Meanwhile, the knowledge transfer strategy of bringing science and society together has led to a growing *bureaucratization of science* with new professionals emerging to facilitate the closure of the gap—*knowledge brokers*, *implementation science/knowledge specialists*, and similar intermediaries. Yet, the shortcomings of this model mean that continuous challenges in closing the gap are not the responsibility of these professionals alone. Policy makers also began to reconsider their approach to knowledge production and sharing. The idea of knowledge mobilization thus emerged as a means to trigger deeper structural changes, not only within academia but in *knowledge society* in general, a society in which 'academic science' is an embedded social institution. That is, where any knowledge production and sharing that takes place within academic settings is also enabled and constrained by broader social forces. Consider, for example, the different philosophies and interpretations that exist between the language of the 'end user' and the 'knowledge user' (see Box 5.1).

Box 5.1 The Knowledge User

'Knowledge mobilization' is part of a broader semantic cluster that also features such concepts as 'knowledge users.' This semantic cluster includes the ideas of *open science*, *open access* to research data and infrastructure, *research networks*, *community-based research*, *public accountability*, and *social responsibility*. In an attempt to achieve engaged research, consider, for example, employing the term 'knowledge users' instead of 'end users.' While the proposed concept may not solve all issues in the research process, it does serve to challenge the idea and power of experts by elevating the status and contributions of research participants. The idea is not just to empower various stakeholders but to change the way we think about knowledge creation in the knowledge society, thus giving credit to the multiple ways in which communities of practice and knowledge contribute to the mobilization of knowledge through the various modalities of knowledge production, translation, transfer, and exchange.

Expand Knowledge Practices and Systems Beyond 'Twentieth-Century Models of Science'

In recent years, a number of the fundamental twentieth-century approaches to science have been scrutinized. This includes an understanding of academic knowledge production as a rational and linear process (see Godin, 2006, for an overview of 'linear models' of knowledge production) that is often referred to as 'positivist' science or a positivist paradigm of research. This suggestion highlights how new models of critically engaged and reflexive practice require knowledge practices and systems to be extended beyond rational, linear, and positivist interpretations of science and research practice.

Positivism offered a restrictive scientific paradigm of linear knowledge production that favored a narrow spectrum of selected (i.e., objective) methodologies and particular kinds of evidence that suppressed alternative evidence and knowledge production such as 'subjective' knowledge and the social sciences. Positivism (or a positivist interpretation of science) has been criticized for its reductionism, universalism, objectivism, and the preference given to stability, quantity, and linearity (see Habermas, 2015, for a critical discussion of positivism). Yet, the shadows of the positivistic worldview and distinctions between models of science as either 'hard' or 'soft' science, and the differential weighting of such models, prevail in the tendency to fund research such as the gold standard randomized control trial.

Further, the idea of linearity inherent in the positivist model has informed processes of knowledge production and knowledge sharing. Research governance models, for example, were founded on the positivist ideology of twentieth-century science. In this context, implementation science and the models of knowledge transfer designed to close the gap between scientific discovery and development of applied solutions were themselves based on the same linear model of science and thus subject to its limitations. These models of practice failed to recognize that science was a socially embedded institution with multiple associated challenges and that knowledge production takes place within particular paradigms rather than simply as a linear process (Kuhn, 2012, illustrates that knowledge production is subject to paradignmatic changes). It also overlooked how science, and the acts of producing and sharing knowledge, took place within and against a larger shifting global context.

As such, science policy based on rational and linear models of knowledge and practice have created tensions in academia and introduced barriers between science and sectors of society. Some of the most notable examples are between science, art, and/or education, as well as alternative or collaborative approaches to knowledge production and sharing. Other problems, for example, involve how positivism has located the researcher in the dominant role of 'expert' and 'knowledge producer,' with a research subject who is a passive participant and 'end user' or recipient/receptor of knowledge. Given this, it is not surprising that systems of knowledge production based on positivism were criticized for methodological censorship and, in particular, the imposition of the values and knowledge systems of dominant cultures that suppressed the values and the knowledge systems of various cultural and epistemic minorities.

New practices of engaged research and science thus require that twenty-first-century science reinvent itself as an embedded and reflexive institution. This would mean developing a system that is capable of revising its core principles, recognizing and challenging power relations, such as those between 'researchers' and 'research subjects,' and building inclusive forms of engaged research. It would also involve challenging the ideas of the researcher serving the needs of the community, the assumptions embedded in methods or tools, the taken-for-granted discussions of solutions, as well as 'unanticipated outcomes' or 'unpredictable markets.' The concept of knowledge mobilization plays a critical role in this new vision of science, since it encourages innovative co-creative research practices and governance solutions. Knowledge mobilization is not a specialized field *between* science and society; it is rather a process of reflexive engagement with scientific processes and social institutions *across* knowledge society in general, which involves other modalities of knowledge production, including such expansive and critical fields as alternative and independent research (see Box 5.2).

Box 5.2 Embracing and Engaging with Alternative Modes of Knowledge Production

Consider, for example, the field of rehabilitation sciences, where treatment modalities, such as yoga, sport, dance, or art therapy, considered largely marginal only a few years ago are now becoming more legitimate and mainstream as approaches in rehabilitation research and practice. The medical model, although normative in its aims of rehabilitation, now accommodates a wider spectrum of experimental knowledge systems and a widening acceptance of such practices. This includes a new openness and willingness to work with and within traditional and indigenous knowledge systems. Previously, 'positivist science' in its normative capacity would have only promoted particular expert knowledge while excluding, censoring, or suppressing various 'anomalies' or alternate approaches to knowledge. Such examples open up avenues for a much-needed discussion on the ethical and political dimensions of academic research. Looking back, how can 'we' compensate for the damage inflicted by normative knowledge systems? What can we do to avoid similar experiences in the future?

Develop a Culture of Knowledge Mobilization

Changing well-established ideals and practices requires culture change within science and academia as a whole. Policy makers have introduced a number of initiatives that may alter and/or potentially lead to the collapse of the knowledge transfer paradigm and the emergence of a *new research infrastructure* that enables *public participation* in research and development. While these initiatives are an important step in building a new knowledge production infrastructure, actual change needs to take place on the ground, when research institutions and individual researchers adopt innovative practices and build them into their day-to-day research practices. 'Knowledge mobilization' has the capacity to transform the ways that a knowledge society functions, but only if researchers actualize its potential through innovative *reflexive* practices of research and action.

By reflexivity, we mean critical engagement with our own knowledge and practice and the broader institutional initiatives and norms of knowledge production and sharing. Reflexivity involves a process of self-reflection and reconsideration of taken-for-granted practices of power and knowledge that exist within and across a range of settings. For example, as researchers we may begin to think of ourselves simultaneously as 'knowledge users' and 'knowledge producers' who co-construct and share information across contexts and teams, which may involve resistance and differences in perspective. Reflexivity in knowledge mobilization is thus an idea of conceptualizing a process of self-awareness as well as project/team awareness, experience, and self-identity in practices of knowledge co-production (see Tskekeris, 2010, for an overview of the concept of reflexivity).

In a reflexive practice of knowledge mobilization, the questions for the critically engaged researcher become: How can *individual researchers* and *research networks* implement ideas as *knowledge co-creation*, *citizen science*, *community-initiated studies*, and cooperation with alternative knowledge systems? What mechanisms exist to support involvement and *open access* to research data and infrastructure? How might the idea of the rethinking of the public from passive *informants/end users* to *collaborators/co-researchers* translate in individual research projects? How will it transform them? While answering these questions may seem beyond the scope of individual research projects and researchers, they represent a series of questions that can be asked as part of a commitment to reflexive and engaged research.

Changing the culture of knowledge transfer thus rests on a working definition or practice of knowledge mobilization. Our suggestion for a reflexive and engaged practice is to operate from an open understanding of knowledge mobilization, to exercise curiosity, and to accept a plurality of approaches to knowledge production across various fields. In doing so, knowledge mobilization can become a reflexive process of continuous innovation in the production of new knowledge and an ongoing engagement with a range of established practices and institutions, simultaneously challenging and transforming them. In this sense, resistance and the need for ongoing dialogue can be expected and is part of knowledge mobilization. Unlike 'knowledge transfer,' reflexive and engaged research is a political act that creates stronger meaningful links between academia and a knowledge society, removes existing barriers that block or slow down public participation and knowledge flows, and engages in ongoing meaningful discussions and innovation (see Box 5.3).

Box 5.3 From the Ivory Tower to Transformative Research

Knowledge mobilization is a transformative research practice, whereby funding agencies, research networks, and individual researchers reflect on the noted criticisms, such as 'ivory tower research.' These include, for example, the criticism of the disconnect between academic research portfolios and real-life challenges, the inability of the public to influence or contribute to research agendas, the lack of transparency in research decision-making, and limited public access to research infrastructure. An iterative response to researchers moving to models of transformative research could then be accompanied by a move whereby funding agencies change their criteria to support exploratory and interpretive studies and whereby researchers formulate their research questions together with communities and create mechanisms of support to ensure recognition for the time and complexity involved in such processes.

Research Impact Begins with Changes Within the Academic Context

The final idea for researchers to become more engaged with knowledge mobilization is to consider (and perhaps advocate) for change in academic structures and contexts. The expansion in the mission of universities as places to create and share knowledge in new ways has created tensions between these new expectations and demands and the system of academic rewards. For example, existing metrics of academic success, such as publication in high-ranking discipline-specific journals, continue to place an emphasis on particular types of research rather than on education or training and the more engaged approach to the co-creation of knowledge.

Current governmental initiatives have redefined objectives around the training of highly qualified personnel, as well as social and economic impact. The expectation is that this will prompt academic systems to reform their approaches to academic performance evaluation. However, academic systems have a degree of rigidity, meaning that these responsibilities fall on researchers themselves. Researchers often have to navigate a complex terrain to find a balance between competing demands such as educator/scholar, knowledge co-production within the typical academic guidelines for tenure and promotion, as well as current scientific practice and methodology.

While it may be possible to design metrics that register whether training is adequate for the new economy, or how highly qualified personnel are able to engage in working across disciplinary fields and sectors of society, such metrics would probably only achieve institutional or sectoral significance. A more challenging but relevant agenda to the engaged researcher is to understand and collect data on how researchers implement the ideas of responsible conduct or provide service to communities and reward them accordingly. For example, if research is expected to be truly inclusive and representative, the public and those involved in the research should also be fairly compensated for their involvement, have access to research results in lay language, as well as the understanding to meaningfully collaborate with researchers and make use of new findings. Designing a system capable of integrating these parameters, however, is a challenging task. Consider the example of ethics in research (see Box 5.4).

Box 5.4 The Extended Ethical Questions of Research

Researchers' engagement in science policy and governance through their participation in funded projects is an area where critically engaged processes can be used to revise or alter practices. For example, research ethics covers a broad range of issues that extend beyond the instrumental idea of simply passing an ethics review. Questions of ethics are intertwined with related issues of academic integrity and the relationship between sponsors of research and society.

(continued)

Box 5.4 (continued)

The following questions can help to guide researchers and institutions that are attempting to engage in knowledge mobilization from a critical and inclusive framework: How should researchers respond to offers of funding from industry or state agencies that may be perceived as an attempt to legitimate harmful practices, exploitation, or the violation of human rights? How should researchers respond to impact agendas that may be driven by particular interest groups, or the overall motive of profit, as is possible with commercialization? How can budgets be used appropriately to compensate for participation that does not further exploit vulnerable groups?

Conclusion

The key ideas that have been discussed help to broaden thinking about knowledge production and sharing and provide important areas of reflection to engage critically with new expectations around knowledge and impact. In other words, knowledge mobilization, if approached critically and reflexively, may offer a potentially non-reductionist way of thinking about goals such as the co-production of knowledge and social impact. We are not suggesting that researchers and teams abandon all previous tools and resources. On the contrary, we suggest that they engage in critical and creative forms of thinking about and planning for impact that simultaneously interrogate the boundaries that are said to exist between science and society.

The challenge for current and future researchers is thus to employ existing resources on impact and impact planning critically and to raise questions about any conceptual fragmentation of the sphere of knowledge production and criticisms of modes of sharing knowledge. The task for the engaged researcher is to engage in a reflexive process of knowledge production through innovative and collaborative research practices that reduce barriers and delays to knowledge generation and the mutual exchange of ideas and knowledge.

Key Messages

- Funders and policy makers increasingly expect research to have social and economic impacts and benefits. This requirement puts pressure on research networks and individual researchers to engage in new forms of knowledge production, impact planning, and assessment of research outcomes.
- There is a gap between knowledge and practice in academia and great distance in connecting knowledge with society in ways that are deemed valuable.
- Knowledge transfer approaches had limited success in bringing science and society together.
- Knowledge mobilization was introduced to rethink and restructure the processes of knowledge production that supported conceptual and institutional separation of science and society.

- If knowledge mobilization is to be successful, researchers must be aware of the shifting contexts within which they work, must engage critically with academic systems in general, and question normative approaches to data collection, research sponsors' agendas, barriers to data access, and mandated understandings of research impact.
- Researchers should see themselves as innovators whose challenge is to create a new culture of knowledge mobilization that invites and encourages all of society to engage actively and critically in the processes of knowledge production.

References

Godin, B. (2006). The linear model of innovation: The historical construction of an analytical framework. *Science, Technology, & Human Values, 31*(6), 639–667.

Habermas, J. (2015). *On the logic of the social sciences* (S. W. Nicholsen Trans., & J. A. Stark Trans.). Hoboken, NJ: John Wiley & Sons.

Kuhn, T. S. (2012). *The structure of scientific revolutions* (2nd ed.). Chicago: University of Chicago Press.

Tskekeris, C. (2010). Reflections on reflexivity: Sociological issues and perspectives. *Contemporary Issues, 3*(1), 28–36.

Van den Akker, W., & Spaapen, J. (2017). *Productive interactions: Societal impact of academic research in the knowledge society. LERU position paper*. Leuven: League of European Research Universities. https://www.leru.org/files/Productive-Interactions-Societal-Impact-of-Academic-Research-in-the-Knowledge-Society-Full-paper.pdf.

Part II
Working Collaboratively

Judith Sixsmith

In recent years there has been a growing conviction in research circles that research aimed at solving societal problems needs to embrace expertise from different disciplines and sectors to better capture the complexities of those problems and to provide more effective solutions. This has brought about a recognition that academic or scientific expertise provides one necessary source of information, while professional and experiential expertise provides information grounded in the practicalities of everyday life. In more traditional research designs, researchers work to identify the research problem. They then create the research design and conduct activities such as data collection, interpretation and construct knowledge, recommendations, and policies or technologies to address the research problem. All of this is usually structured by a mutually understood research process underpinned by core values such as being objective, value-free, replicable, and valid and as having a shared understanding of practical issues including ethical considerations, standard communication practices, and achievable timelines. However, when different disciplines and sectors are brought together, such mutual and shared understandings cannot be taken for granted. Working collaboratively with people, sectors, and organizations who hold very different values and operate via different practices can cause considerable difficulties for research projects, even sometimes leading to project failures. Yet all too often, research project teams and management structures focus almost exclusively on the research itself, rather than on team or partnership building and collaborative working. In this part, challenges associated with working collaboratively in transdisciplinary research partnerships and practices are presented in a series of *how-to* chapters supplemented by descriptive case studies and learning activities.

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In Chap. 6, Fang et al. examine the challenges involved in building effective partnerships within transdisciplinary projects where the importance of engaging the appropriate expertise in addition to brainstorming about required expertise and skills with diverse stakeholders is emphasized. Focusing on the partnership itself is an important starting point for any project and holding discussions about necessary partners, expertise and skills should recur throughout the different stages of the project. Attention to the specific requirements of partners including time limitations and scheduling shows respect for their contributions while addressing language and sectoral core value differences helps to build effective partnerships. Fang et al. suggest that building effective partnerships can benefit from the use of nontraditional methods such as community-based participatory approaches. Finally, to ensure the successful integration of all voices around the table and to integrate different knowledge bases, integrated (co-creation) knowledge translation approaches are suggested, such as World Cafés and co-created dissemination materials. These ideas are illustrated in a case study by Fang et al. demonstrating a community-based participatory approach to developing optimal housing for low-income older adults in Canada in which workshops and deliberative dialogue sessions were used to enable strategic joint planning, making visible the experiential knowledge of older adults and creating a space for them as active place makers in the process. Finally, the problem of identifying key stakeholders is addressed in Sixsmith's learning activity. Here, the use of a stakeholder expertise mapping tool or developing an *actor model* (Lunn, Sixsmith, Lindsay, & Vaarama, 2003) is proposed.

Once a transdisciplinary team has been formed, then attending to team dynamics becomes important, a topic covered by Sixsmith et al. in Chap. 9. They suggest the development of Memorandums of Understanding and Terms of Reference within teams such that all partners and partner organizations are clear about their roles, the constitution of the team, and processes governing joint working. If the processes for joint working, resolving conflict and collaborative decision-making are clear at a project's outset, then teamwork becomes more transparent and easier to negotiate if and/or when difficulties arise. In addition, Sixsmith et al. maintain that attention to the fluctuating power dynamics within a team, perhaps through *appreciative inquiry*, is critical to building the trust and mutual respect necessary for enabling all voices, including junior researchers and experiential stakeholders to be heard and acted on in the best interests of the project. As a learning activity for effective team working, Yeung explains the value of planned movement through different stages of a project in terms of *forming*, *storming*, *norming*, *performing*, and *adjourning* processes. Yeung's learning activity focuses on the project *forming* aspect and identifies the kinds of questions that can be asked to understand, define, and support team development.

Perhaps one of the key areas of concern when conducting large collaborative, transdisciplinary projects revolves around engaging with experiential stakeholders. This can be particularly difficult when researching with hard to find, hidden (do not want to be found), and seldom heard (rarely listened to) populations as discussed in Chap. 11. In this chapter, Freeman et al. discuss making initial contact, recruitment (despite mistrust, participation fatigue, harm, stigma, disclosure, and exploitation), retention (including a focus on relationships and being flexible to change), and sampling (consider feasibility, cost-effectiveness and that no one strategy fits all situations). Two case studies accompany this chapter; firstly the Freeman et al. case of digital storytelling stories with Elders and youth in the Nak'azdli First Nation highlights the need to spend considerable time (months to years) building meaningful relationships to develop trust and mutual understanding, consider the specific needs of the unique population, remain flexible in terms of research practices and processes, as well as take direction from community leaders. The second case study by Skinner et al. points out that when working with at risk groups, thinking through and attending to participation barriers as well as respecting cultural aspects of the group can make the difference between project success and failure. Freeman and McLeod offer an interactive, scenario-based learning activity intended to help researchers identify and address unexpected challenges when trying to recruit, design a sampling strategy, and develop a research plan involving hard to reach, hidden, and/or seldom heard populations.

Freeman et al., in Chap. 15, further address the issue of building effective research relationships with hard to reach, hidden, and seldom heard populations where participatory, authentic, meaningful, and beneficial collaborative working is emphasized. Several steps are recommended when working with populations who may feel suspicious (often with good reason!) of authorities and *outsiders*: establishing mutual respect through valuing diverse experiences, developing trusting relationships through reciprocal relations and/or activities, shared learning and ensuring that relationships are recognized beyond the confines of the project. The time-intensive nature of relationship building is highlighted, together with a reflexive stance toward one's own and others' attitudes, experiences, and perspectives. Again, attention to issues of power imbalances and control is necessary, and working together to develop ownership of the project, its outcomes and outputs, and celebrating project successes together can be pivotal to success. Many of these principles can be seen in Sixsmith's case study on developing a passive, home-based, 24-h smart distress monitor with frail, sometimes housebound, older people where attention to physical health, mobility, emotional, and social well-being is described.

Most research, and all applied research, has, as its underlying purpose, the aim to address real-world problems. To do this within transdisciplinary approaches, Wada et al., in Chap. 17, set out four key strategies: community involvement throughout the research process to identify and understand real-world problems; co-develop strategies for translating project outcomes and outputs; mobilization of research outcomes in appropriate format and disseminated to change-maker stakeholders; training researchers to implement transdisciplinary research; and planning commercialization strategies at the outset of the project, together with industry partners to translate research outputs into positive impacts on real-world problems. The importance of training and capacity building for impactful research in the real-world is identified in Sixsmith's case study on the ENABLE-AGE project (aimed at developing a new way of thinking about how the home environment contributes to the health aging) alongside mobilizing knowledge (in dedicated project glossaries and project manuals) to support understanding of project aims across diverse groups.

The notion of education and training for innovation and impact is picked up in Chap. 19, wherein Yeung and Sandassie present issues of leadership, project management, stakeholder engagement, and effective communication as important areas of graduate education. They suggest that focusing research actions on SMART goals, using business management tools and leadership techniques, are the central domains of learning for research to equip future researchers for research that makes a positive difference in people's lives. Sandassie and Yeung offer a case study of a research network, AGE-WELL's Summer Institute (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence), which utilizes theory-informed pedagogy to engage trainees in a transformative learning process thereby challenging trainees' assumptions and expertise through engagement with external stakeholders and by providing space and opportunities for ongoing critical reflection.

Finally, Baldie et al., in Chap. 21, argue that vibrant research cultures are vital to creating innovative solutions to real-world problems. Such cultures encourage rather than stifle new ways of thinking by developing a challenging and exciting vision that everyone owns and can engage with, paying attention to researchers and their career progressions, creating safe spaces to reflect on strengths and get support without judgment, and taking time to reflect on and celebrate work and benefit from skilled mentorship. Here, research is not just about the commitment to and expertise in research activities, but about the whole culture that research is embedded it.

Reference

Lunn, K., Sixsmith, A., Lindsay, A., & Vaarama, M. (2003). Traceability in requirements through process modelling, applied to social care applications. *Information and Software Technology, 45*(15), 1045–1052.

Chapter 6
Building Partnerships and Co-creating with Diverse Stakeholders

Mei Lan Fang, Alisa Grigorovich, Mineko Wada, Pia Kontos, and Judith Sixsmith

The Challenge

As populations and life expectancies increase, interventions to enhance health, well-being, and quality of life become more intricate and more complex. Often, new health interventions and innovations designed to counter progressive age-related challenges never achieve a real-world impact because the product never makes it into real-world settings, or if it does, it is found to be irrelevant or ineffective for addressing the problem at hand. To develop health interventions that have *real-world* impacts (as described in Wada et al. Chap. 17) requires collective, innovative problem-solving, integrating knowledge and expertise from both academic and non-academic disciplines and sectors, as well as the people we aim to serve. This fundamental idea of co-creation as an inherent part of transdisciplinarity, described more fully in Grigorovich et al. (see Chap. 4), stems from participatory action research, a research approach which is an important part of transdisciplinary working (TDW).

Partnership building requires working together in teams comprised of diverse stakeholders with different training, skill sets, and perspectives. This is a key aspect of TDW. This is a crucial component in the research design, development, and implementation process for creating interventions that are relevant, effective, usable,

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and appealing to different populations. The most critical, yet fundamental aspect of partnership building and working with diverse stakeholders is the collaboration across disciplines, sectors, and communities. In this collaboration, where the lines between science and society become blurred, the results include the creation of new research questions, novel methods, diverse knowledge sources, and nuanced solutions that serve a broader, collective objective. This chapter describes three research projects to demonstrate the key aspects of *how-to* build partnerships and co-create solutions to tackle health-related challenges in real-world settings:

- Importance of engagement and brainstorming with diverse stakeholders in all aspects and steps of a project.
- Using nontraditional methods to build partnerships in research.
- Developing new knowledge with diverse stakeholders through integrated knowledge translation.

Key Ideas

Engagement and Brainstorming with Diverse Stakeholders

It is important at the start of (or even before) a project to determine the problem area with people. This involves, for example, the development of ideas. It involves, as well, understanding the issue and those directly affected by it. Having brainstorming discussions with diverse stakeholders with different backgrounds and expertise at the outset is the first step toward establishing project partnerships. The project example presented in this section demonstrates the value of having partners and team members from diverse disciplines and sectors.

The Rehabilitation Music Project (Alias). This transdisciplinary project (Moreno, 2012) involved developing music rehabilitation software for improving the cognitive health of older adults. As a part of this project, the first step was to identify what expertise and skill sets were needed to provide a comprehensive understanding of the problem area, i.e., to develop a map of who should be *at the table* (see Box 6.1).

Box 6.1 Who Should Be at the Table?*
The music project was guided conceptually by transdisciplinary working (TDW) to develop a program of music training that enhanced the cognitive health of older adults. An assessment of the complexity of the problem made it clear that expertise from academics from several disciplines (music, teaching, psychology, clinical practice, neuroscience, computer programming, and engineering) was required to ensure that the music training program was effective, in terms of its usability and its ability to improve cognition.

(continued)

Box 6.1 (continued)
However, initial brainstorming efforts across the research team highlighted the need for the inclusion of valuable everyday knowledge of older adults to identify how they listened to music and which music they enjoyed. The effectiveness of the rehabilitation software was traced by the project team to (1) the generation of specific notes (identified by neuroscientists) that influenced cognitive skills such as memory, attention, and intelligence; (2) targeting the contributors to cognitive aging (identified by clinicians and neuroscientists); and (3) implementing teaching and learning methods conducive to older adults (identified by music teachers and older adults). Of course, the software would not exist without the design and development efforts of the computer programmers and the software engineers.

Note. *See Boger et al. (2016).

By applying TDW, the research development team contributed to the successful development of the music training software by prioritizing the following key features in the project:

- Doing research that is of mutual benefit to the technology industry and to society.
- Developing a research process that is *iterative* and *interactive* meaning that the interventions are developed together with persons of varying levels of expertise and new knowledge are derived from integration of both scientific studies and everyday experiences.
- Integrating and implementing knowledge mobilization efforts or ways to generate different knowledge formats so that the information is accessible for individuals from different disciplines and sectors.

It was clear that acknowledging and utilizing the diversity of skill sets and expertise were crucial for the development of the intervention. However, it is important to note that *doing* transdisciplinary work is not straightforward. For example, an initial challenge resided in overcoming disciplinary and sectoral language differences since various members of the team instinctively used words to describe purpose and meaning that were specific to their field (e.g., end user, user interface, mild cognitive impairment). This is a common issue encountered within transdisciplinary research, i.e., understanding words differently. This can result in misunderstandings that undermine the project and thus should be resolved early on in project discussions,

Related to this problem was the lack of understanding by team members of the scope and limitations of the different disciplines in terms of theory, methods, and even work styles (i.e., music theory is important in developing music training but less effective for determining the logistics of software programming). Additionally, coordinating schedules (i.e., availability and place), productivity (i.e., level of contribution), and adhering to deadlines were difficult as team members were highly dependent on one another for various aspects of the work plan. To address these challenges, a communication protocol (see Box 6.2) was established that enabled clearer understandings of meanings and ideas during discussions and meetings as well as clarifying the roles and responsibilities of each team member. Developing a communication protocol at the start of the project is important for relationship building (a cornerstone of building effective partnerships!). Having clear communication channels can prevent miscommunication. It also helps build trust and accountability as misunderstandings associated with project deadlines, deliverables, roles, and responsibilities can be avoided within and across different teams.

Box 6.2 How Do We Improve Our Communication?*

Open and honest communication builds trust and accountability. These are instrumental components of successful collaborations and are very much part of the *transdisciplinary attitude* to research. Without open and honest communication, problems that arise can include: multiple partners and teams working on the same task, misinterpretation of messages through ineffective modes of communication such as emailing, both of which can ultimately result in poor rapport between partners and teams. At the start of the project, the team can collectively formulate a communication protocol. This involves establishing: (1) a common language (e.g., protocol for querying and explaining terms and jargon during discussions and meetings); (2) frequency of communication (e.g., weekly, monthly, quarterly); (3) platform for engagement (e.g., Skype, Vidyo, Zoom), etiquette in practice (e.g., only during regular business hours unless urgent, which must be stipulated); (4) processes for conflict resolution, channels to bridge connectivity (e.g., through administrative gatekeepers or directly to the individual); and (5) modes of communication (e.g., in person, group meetings, one-on-one meetings, by phone, via remote platforms). Considering all of these communication components, it is important to reflect on the most effective aspects for communicating with each type of partner in different circumstances, particularly for individuals such as older adults who may have less technological know-how and may have other everyday challenges such as mobility issues. Also, some partners might find it more difficult and time consuming to write emails and prefer telephone calls, while others prefer face-to-face meetings or videoconferencing.

Note. *See Suter et al. (2009).

In the Rehabilitation Music Project, the challenges of TDW were outweighed by the productivity of the team. Collaborative working and utilizing diverse expertise generated a solution to a problem that integrated both scientific and social understandings of the issue (i.e., cognitive challenges individuals experience as they age). This resulted in a technology intervention focused on improving cognition through music therapy that addressed a key aspect of a complex health issue, i.e., cognitive deficiency in old age.

Using Nontraditional Research Methods to Build Partnerships

Working with a diverse group of stakeholders from various different backgrounds, knowledge bases and expertise can be challenging. Often, traditional research methods (i.e., observational studies such as conducting surveys and/or using a single method to understanding a complex problem) do not account for diverse needs and understandings of various stakeholder groups and often will not have processes in place for stakeholder engagement in the research plan. One approach to enhance meaningful engagement of stakeholders in research is the use of community-based participatory research (CBPR) that encompasses methods such as in-depth interviews (Guion, Diehl, & McDonald, 2011), photovoice (Wang & Burris, 1997), and deliberative dialogue (Plamondon, Bottorff, & Cole, 2015). The project example presented in this section demonstrates the use of these methods to establish and maintain partnerships mainly with research participants as project partners.

The CBPR Seniors' Housing Project (Alias). This transdisciplinary project (Fang et al., 2018) applied a CBPR approach to explore experiences of older adults transitioning from a deteriorating 3-story low-rise affordable seniors' housing community into two new build 16-story high-rise towers. The project aimed at generating shared solutions for mitigating social isolation in the new community (see Box 6.3).

Box 6.3 Why Are Community-Based Approaches Valuable for Building Partnerships?*

This project's CBPR approach was built on values derived from the disciplinary teachings of community psychology and focused on principles of social justice, reducing oppression, and giving voice to people who experience marginalization in their everyday lives. CBPR is founded on principles of equality and diversity to provide local space for persons with less societal power so that they are able to influence research and improve their lives, as partners, on issues that directly affect their personal interests. Guided by this approach, the researchers worked with older adult tenants to ensure that they had the knowledge and resources to communicate effectively with property developers, managers, service providers, and other professional stakeholders to increase the chance of their interests and needs being met. This project applied a number of strategies (see Box 6.4) for participant engagement, including in-depth interviews and photovoice as well as deliberative dialogue sessions with municipal government representatives and service providers to ensure that discussions resulted in actionable next steps.

Note. *See Sixsmith et al. (2017).

To engage stakeholders in the CBPR Housing Project as partners, CBPR methods were used (see Box 6.4) that constituted a staged-engagement approach to:

1. Prioritize voices of tenants' voices at the start of the project through in-depth interviews and photography sessions.
2. Provide findings that concerned older adults' experiences, thoughts, and feelings about the relocation to professional stakeholders (i.e., developers, housing providers, and government officials) for discussion and co-development of ideas (i.e., to improve tenants' quality of life) during deliberative dialogue.
3. Establish commitment from service providers and municipal government representatives to join the research project not only as participants but also as facilitators for change through deliberative dialogue.

Box 6.4 Which Methods Used in CBPR Approaches Can Enhance Partnerships?*

In-depth interviews

Prior to moving into the two new builds, most tenants were eager to talk about the relocation. One-on-one in-depth discussions with seniors at the place of their choice and in their native language allowed for more holistic understandings of participants' relocation experiences and the necessary services and amenities required to support them to mitigate social isolation. This method facilitated the building of rapport between the researcher and seniors as researchers moved into the next stages of the project.

Photovoice

Photovoice is a visual method using photography. This method stems from qualitative participatory research used to explore personal experiences of a particular research area of interest. As the research required in-depth understandings of the places in the home and community that were meaningful to participants, the photovoice technique was required to help seniors present this information through taking photos of situations and places.

Deliberative dialogues

This is a method for generating thoughtful and open discussion. Deliberative dialogues provide opportunities to generate data for analysis, engage participants, and create research evidence. The end goal of deliberative dialogues is to determine a set of action items to create positive social outcomes. Deliberative dialogue sessions enable a diverse team to jointly expand ideas for increasing opportunities for social engagement for older adults. It also, at the same time, enhances partnerships among stakeholders who all have diverse training experiences, skillsets, and backgrounds.

Note. *See Fang et al. (2018).

The CBPR research approach enabled a successful partnership that generated a number of positive outcomes for the community. Firstly, engagement methods selected for the project helped tenants' voices be heard by professionals. This allowed them to influence the decision-making as partners and gave them input into the planning and use of the shared amenity space in the new building. Secondly, the CBPR approach encouraged strategic planning with local service and housing providers to enhance social interaction and programming in the shared amenity spaces (common in condominium-style buildings) by bringing in community and neighborhood supports for older adult specific programs and activities and addressing contextual challenges to service provision (through ongoing and deliberative discussions).

In terms of the new building, a number of changes were implemented as a result of the CBPR approach to create an improved living environment for older tenants, including: the establishment of a social committee, led and organized by tenants living in the building; several annual cultural and social events funded by building management; and a number of ongoing in-house age-friendly activities and strategies for generating income to fund equipment and events. The older adults were actively involved in selecting, creating, and acquiring the activities, services, and supports they desired and, ultimately, were able to determine how they would use the building's shared amenity spaces to create a more socially engaging environment.

Co-creating Knowledge Through Integrated Knowledge Translation

Developing new ideas and health solutions together with a diverse group of individuals require strategies that are useful and relevant to practice and ultimately move science forward. One approach for creating new knowledge with diverse stakeholders is through integrated knowledge translation (iKT) (Bowen & Graham, 2013). iKT refers to integrated and collaborative working between researchers and non-researchers with the aim to create knowledge that is relevant and of use in real-world settings (Battersby et al., 2017).

The Digital Divide Project (Alias). This knowledge generating project (Fang et al. in press) explored the digital divide for middle-aged and older adults focusing on their access to and use of information and communication technologies (ICTs). ICTs refer to technologies that provide access to information through communications technologies. These can include computers, Internet, wireless networks, cell phones, tablets, and other communication mediums.

Guided by the iKT definition, team members searched for and brought together literature published over the last decade to better understand the current state of the digital divide focused on middle-aged and older adults. The iKT approach was selected to ensure that: relevant research questions were asked which addressed the problem area; useful dissemination channels were developed; and pertinent knowledge and expertise beyond the reach of academia were included as a part of the

Box 6.5 What Does an iKT Co-creation Project Look Like?
Researchers worked with a local community older adults' organization to formulate a research question to address challenges older adults faced when accessing online services that required the use of information and communication technologies (ICTs). This community organization was also interested in using project findings to inform their work practice. Their initial involvement contributed to the development of the research approach and subsequently to the making of other research decisions that helped better inform the problem area of the digital divide. The digital divide is about understanding the differences and challenges between groups of individuals when accessing and using technologies. This is especially relevant as society becomes increasingly involved in the *digital world*, where everyday tasks will depend on knowing how to access and use ICTs. The digital divide was understood in the project as the unequal access to the benefits of ICTs (particularly by marginalized groups such as some older adults) due to limitations of income, education, lack of social support, motivation, physical access, and/or capacity to use. This iKT project included a realist synthesis review, two World Café knowledge events, and dissemination materials. Together, two World Cafés (a knowledge co-creation iKT strategy) were conducted with stakeholder groups, which guided, informed, and contributed to the data analysis, synthesis, and dissemination of findings. See Fang et al (2019).

Box 6.6 Some iKT Strategies for Co-creating Solutions to Enhance Seniors ICT Access and Use?*
Continuous collaboration with community partners
Regular team meetings (prior to the submission of the grant proposal) in non-academic settings (e.g., cafés) were organized with partners to develop and refine research goals and objectives. Throughout the project, the research team worked closely with partners to refine the method and ensure that findings were translated into practice.

Knowledge Co-creation via World Café Dialogue
World Cafés are often used as a method for engagement to generate effective dialogue, knowledge exchange and strengthen relationship building. The use of this strategy helped capture the tacit knowledge of older adults, industry professionals, academics, and service providers of ICT used by middle-aged and older adults and supported the dissemination of findings through public involvement and dissemination.

(continued)

Box 6.6 (continued)

Co-production of Accessible Dissemination Materials

Central to this iKT project was producing accessible outputs with partners to share with participants that included seniors, service providers, academics, and industry professionals. The synthesis of research findings and World Café dialogue informed the development of a final report co-designed and co-written by community partners and researchers. Having perspectives of community stakeholders helped provide context to various ICT access and use challenges otherwise unknown to researchers. This resulted in a more informative, engaging, and useful report for policy makers, service providers, and other researchers.

Note. *See Battersby et al. (2017).

knowledge synthesis. Three primary iKT strategies used in the project were: (1) continuous collaboration with community partners; (2) knowledge co-creation via World Café dialogues (see resources and support section); and, (3) production of accessible dissemination materials. These are described in Box 6.6.

The iKT approach used in this project ensured that the research explored a relevant question resulting in practical implications for the important topic of the digital divide. One key challenge experienced during the project was that the main contact at the community partner organization had moved to another position midway through the project. Her successor was less invested in the research, and as such, did not prioritize the research partnership as highly on her agenda. This is a common occurrence in collaborative research initiatives where key individuals in a project leave partly or midway through. Given the high probability of such difficulties, a memorandum of understanding alongside a terms of reference document (discussed more in-depth in Sixsmith et al.'s Chaps. 6, 9, 16, 24, 27) formulated at the start of the project, can help keep the project on track.

The key ideas introduced in this chapter present research methods and practices that facilitate partnership building and co-creating of ideas and solutions within research teams and across partnerships:

- Key idea I emphasizes the value and importance of engaging and brainstorming with diverse stakeholders prior to, at the start, and throughout the research project.
- Key idea II demonstrates the combined use of nontraditional research methods (such as in-depth interviews, photovoice, and deliberative dialogue) to build and maintain partnerships in projects.
- Key idea III presents the benefits of using an integrated knowledge translation approach to create, discuss, and share new information with diverse group of stakeholders that is relevant and of use in real-world settings.

To assist with the development and implementation of these ideas, below, we present a useful framework entitled the Product Innovation Pathway (PIP), and subsequently, some additional resources and supports to help organize and deliver your research ideas.

Product Innovation Pathway

Building successful partnerships and working effectively with diverse stakeholders can be accomplished through the use of a set of methods and activities formulated into a *how-to* pathway. To summarize the key ideas presented in this chapter, highlights of primary activities are described in the Product Innovation Pathway (PIP) (see Table 6.1).

Table 6.1 Product Innovation Pathway (PIP) model

PIP level	PIP description	Description
1	Concept	Assemble partnerships (consisting of persons with experience and expertise for the different aspects of the project, see Box 6.1); develop and refine research goals and objectives with partners prior to submitting the grant application for funding; establish a steering committee at the start of the project to develop and guide the research
2	Planning	Host regular steering committee meetings with representation from partners of different disciplines and sectors; develop a fluid communication channel to ensuring clear understandings of what each team member could contribute (see Box 6.2); coordinate the schedules, time restrictions, work flow, and productivity of the team by developing a work plan with the team and not for the team as people are dependent on each other for different aspects of the work
3	Development	Consider the use of nontraditional and traditional scientific methods not only for collecting information but also to disseminate findings, build partnerships, and, ultimately, enhance creative working (see Box 6.4); ensure an iterative process—draw from what is already known (i.e., expertise of partners and their projects) together with new findings, and refine methods and processes
4	Testing	Alongside PIP level 3 actions, use an iterative and action-oriented approach to ensuring the success of partnerships. Information (i.e., lay summaries) about the research (e.g., methods, preliminary findings) should be made accessible (e.g., in multiple formats such as hard copies and emails and in multiple languages) to all partners to encourage active engagement and contribution. Stakeholders should also undertake a more reflexive role in the research process. To validate findings, solicit feedback from stakeholders before any major decision-making takes place, and after achieving major milestones and deliverables to reflect on the research process. Stakeholders should also be involved in providing input to the different iterations of outputs
5	Implementation	Consider the use of an iKT approach (see Box 6.6) to ensure that the research question was addressed and the outcomes have practical implications; use an iKT approach to validate the work, increase knowledge sharing, and identify gaps to address in future research and seek opportunities for building new relationships for future collaborative research initiatives. Alongside level 4, develop accessible outputs to share with participants, stakeholders, and the broader community

Learning More

- Partnerships: frameworks for working together. http://www.strengtheningnon-profits.org/resources/e-learning/online/partnerships/Print.aspx.
- "FOSTERing" Collaborative stakeholder relationships. http://masterfulfacilitation.com/articles/fostering.pdf.
- About knowledge translation. http://www.cihr-irsc.gc.ca/e/29418.html.
- World Café Method. http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/.
- How to co-create the day after tomorrow of your organization. https://www.forbes.com/sites/peterhinssen/2016/11/03/how-to-co-create-the-day-after-tomorrow-of-your-organization/#65fe15e4340a.

Key Messages

- Partnership building should happen even prior to the start of the project.
- Critical to successful partnerships is having team members with the experience, interest, and vested interest in the research outcomes.
- Researchers and innovators need to identify if, when, and how stakeholders should be involved at all steps of the research.
- An iKT approach is a viable option for ensuring that relevant questions are being addressed to ensure real-world impact.
- Many researchers are using nontraditional research methods that are creative.
- To assist in determining *if* and *when* co-creation approaches should be used, research teams can identify their stage of product development by mapping out key activities in the product innovation pathway.

References

Battersby, L., Fang, M. L., Canham, S. L., Sixsmith, J., Moreno, S., & Sixsmith, A. (2017). Co-creation methods: informing technology solutions for older adults. In J. Zhou & G. Salvendy (Eds.), *Human aspects of IT for the aged population*. Aging, design and user experience: Third international conference, ITAP 2017, held as part of HCI International 2017, Vancouver, BC, Canada, 9–14 July 2017, Proceedings, Part I, 10297 (pp. 77–89).

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., Mihailidis, A., … Martin, S. (2016). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490. https://doi.org/10.3109/17483107.2016.1151953

Bowen, S. J., & Graham, I. D. (2013). From knowledge translation to engaged scholarship: Promoting research relevance and utilization. *Archives of Physical Medicine and Rehabilitation, 94*(1 Suppl), S3–S8. https://doi.org/10.1016/j.apmr.2012.04.037

Fang, M. L., Woolrych, R., Sixsmith, J., Canham, S. L., Battersby, L., Ren, T. H., & Sixsmith, A. (2018). Integrating sense-of-place within new housing developments: A community-based participatory research approach. In A. M. Goulding, S. B. Davenport, & A. Newman (Eds.), *Resilience and ageing: Creativity, culture and community* (pp. 129–156). Bristol: Policy Press.

Fang, M.L., Canham, S., Battersby, L., Sixsmith, J., Wada, M., & Sixsmith A. (2019). Exploring Privilege in the Digital Divide: Implications for Theory, Policy, and Practice. *The Gerontologist, 9*(59), e1-e15.

Guion, L. A., Diehl, D. C., & McDonald, D. (2011). *Conducting an in-depth interview*. Gainesville: University of Florida. http://greenmedicine.ie/school/images/Library/Conducting%20An%20In%20Depth%20Interview.pdf.

Moreno, S. (2012). System and method for providing music based cognitive skills development. U.S. patent no. 2012/0090446.

Plamondon, K. M., Bottorff, J. L., & Cole, D. C. (2015). Analyzing data generated through deliberative dialogue: Bringing knowledge translation into qualitative analysis. *Qualitative Health Research, 25*(11), 1529–1539. https://doi.org/10.1177/1049732315581603

Sixsmith, J., Fang, M. L., Woolrych, R., Canham, S. L., Battersby, L., & Sixsmith, A. (2017). Ageing well in the right place: partnership working with older people. *Working with Older People, 21*(1), 40–48.

Suter, E., Arndt, J., Arthur, N., Parboosingh, J., Taylor, E., & Deutschlander, S. (2009). Role understanding and effective communication as core competencies for collaborative practice. *Journal of Interprofessional Care, 23*(1), 41–51.

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369–387.

Chapter 7
Case Study: A Community-Based Approach to Developing Optimal Housing for Low-Income Older Adults

Mei Lan Fang, Judith Sixsmith, Ryan Woolrych, Sarah Canham, Lupin Battersby, Tori Hui Ren, and Andrew Sixsmith

The Challenge

From 2014 to 2017, the Gerontology Research Centre at Simon Fraser University, in partnership with the Richmond Rosewood Senior Citizens Housing Society and the city of Richmond, had overseen the transition of low-income senior tenants from old, dilapidated accommodations into an affordable housing redevelopment project (Rosewood Towers) in Richmond, British Columbia. The challenge was ensuring the seniors experienced their move with reduced stress and to find solutions for

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enhanced social participation to prevent loneliness and social isolation. To do this, a transdisciplinary (across diverse disciplines and sectors) partnership was created among gerontologists, health scientists, a geographer, an ecologist, and a psychologist along with the building's management, and local community organizations (involving the older adult tenants themselves). A series of community consultations using innovative community-based research methods identified the need for housing interventions that build a sense-of-place (Fang et al., 2018) to keep older adults mentally and physically active while providing opportunities to build social capital as well as facilitating an enhanced role for older adults in the design process (Sixsmith et al., 2017).

A community-based participatory research (CBPR) approach was applied using a variety of qualitative methods (i.e., in-depth interviews, photovoice, community mapping, deliberative dialogue, feedback forums, and knowledge cafés) to (1) understand sense-of-place of older adults through multiple views and (2) co-create knowledge and solutions with local stakeholders who have a vested interest in the health and well-being of older adults (see Fang et al., 2016). Through the CBPR approach, low-income senior tenants involved in the forced relocation were consulted (in their own language, as 70% were Chinese) about their experiences, worries, needs, wishes, and expectations as the redevelopment progressed. These older adults were also given seats at the decision-making committee overseeing the redevelopment, as were the researchers. This ensured that older adults' voices were heard and the decisions that were made took their voices into account.

Despite being limited by the fact that the Rosewood Tower reconstruction was already in motion when this project started, the research process had a range of benefits for partner organizations and positive outcomes for the community. For instance, the project provided tenants with an effective voice, enabling them to have input into the planning and use of social space. Furthermore, working closely together with our key partner, the Rosewood Seniors Housing Society, we identified the need for the integration of informal services and activities for older adult tenants within Rosewood Towers. Our collaborative and inclusive CBPR approach in shared workshops and deliberative dialogues (Canham et al., 2018) enabled strategic joint planning with local service and housing providers to enhance social interaction and programming in the shared amenity spaces. This brought in community and neighborhood supports for older-adult-specific programming and addressed several challenges to service provision (through ongoing and deliberative discussions).

For instance, premove interviews with older adult tenants and post-move follow-ups at 6, 12, and 18 months helped monitor and contextualize the impact of relocation on the seniors. There were many negative consequences associated with forced relocation: heightened stress and anxiety; increased rent; less indoor space; shared laundry facilities; fear of high rises; limited parking; pets prohibited; cultural and communication misunderstandings; lack of trust in authority; and additional restricted freedoms (e.g., to decorate their space). The CBPR approach ensured that older adult tenants' concerns were listened to and were allayed where possible by visits to the building, relaxation of regulations (e.g., regarding pets), the benefits of cultural diversity discussed, and communication difficulties addressed. Critical to a more acceptable move was the identification and sharing of the positive aspects of the move:

- Brand new building: privilege of being the first tenants.
- Central location: convenience of living in the city center.
- Moving back to the community: reuniting with friends.
- Affordable rent: with shelter aid for older adult renters' subsidies, rent costs were comparable to that of their previous residence.
- Strict building regulations: no smoking and no drugs.
- No carpet: easy to keep clean for older adults.
- Walk-in shower: enables fall prevention.
- Largely older adult population: surrounded by persons with greater understanding of older adults.
- Safety and security: living in a secure building in a safe neighborhood.

The partnership ethos of addressing negatives, discussing reasons why some aspects of the move or the new build could not be changed, and focusing on the benefits helped to create excitement about the move. Once older adults were living in the new building, there was a sense of pride among tenants.

Outcomes and Impact

This research translated the lived experiences of low-income older adults and community stakeholders into formal and informal supports that fostered meaningful home environments for the older adult tenants, created a role for older adults as active *place-makers* in community planning and development, and attracted much media attention concerning the need for more affordable housing for independent living older adults.

The partnership established during the research process have resulted in real-world impacts, most importantly, improvements in the new build that the tenants appreciated. These impacts included:

- Wi-Fi in the shared amenity spaces, including the reading room, laundry room waiting area, lobby, and lounge areas.
- Exercise equipment in the fitness room.
- Supportive and friendly on-site building management that efficiently addressed tenants' needs as well as general building maintenance, e.g., cleanliness of the building.
- Socially and mentally engaging in-house activities, opportunities for learning, and social services.
- Addressing language barriers (hiring bilingual caretakers, announcements in English and Chinese).
- Social programming committee led by older adults.
- Traffic lights adjacent the building.

- Ongoing funding activities to support social programming.

More broadly, the research resulted in collaborations with the partners for new projects including (1) a community mapping project to inform the implementation of a systems approach to delivering Housing First in metro Vancouver and (2) a doctoral project to explore how low-income older adults of diverse backgrounds construct a *sense-of-place* through inquiries into their place histories as they transition to affordable housing.

Finally, several high-quality theoretical, research, and practice outputs were generated (see Sixsmith et al., 2019). Study findings have been presented at many national and international conferences and used for teaching purposes. Several best practice resources were also developed.

Key Messages

- *Partnership working* is important for generating solutions to complex problems and achieving a pathway toward real-world impact.
- The genuine involvement of older adults through the whole process, including their lived experience insights and voice at the decision-making table.
- The critical involvement of community stakeholders in thinking through cross-sectoral issues and presenting real-world, workable solutions.

Project Details and Team The research was funded by the Vancouver Foundation and brought together several diverse academic and public and private sectoral partners. The academic team was comprised of the principal investigator and two co-investigators (covering Simon Fraser University (Canada), Heriot-Watt University (Scotland), and the University of Dundee (Scotland), a research lead and three researchers. The academic team included English, Cantonese, and Mandarin speakers, and all were experienced in qualitative research. In terms of the new build and its context, organizations in the team comprised a seniors housing society; the city municipality; a developer; a property manager; the Greater Vancouver shelter strategy team; and a representative from British Columbia's nonprofit housing sector. This project brought together architects, civil servants, administrators, managers, and representatives to ensure seniors' perspectives were taken into account.

References

Canham, S., Fang, M., Battersby, L., Woolrych, R., Sixsmith, J., Ren, T. H., & Sixsmith, A. (2018). Contextual factors for aging well: Creating socially engaging spaces through the use of deliberative dialogues. *Gerontologist, 58*(1), 140–148.

Fang, M., Woolrych, R., Sixsmith, J., Canham, S., Battersby, L., & Sixsmith, A. (2016). Place-making with older persons: Establishing sense-of-place through participatory community mapping workshops. *Social Science & Medicine, 168*, 223–229.

Fang, M. L., Woolrych, R., Sixsmith, J., Canham, S. L., Battersby, L., Ren, T. H., & Sixsmith, A. (2018). Integrating sense-of-place within new housing developments: A community-based participatory research approach. In A. M. Goulding, S. B. Davenport, & A. Newman (Eds.), *Resilience and ageing: Creativity, culture and community* (pp. 129–156). Bristol: Policy Press.

Sixsmith, J., Fang, M. L., Woolrych, R., Canham, S., Battersby, L., Ren, T. H., & Sixsmith, A. (2019). Aging-in-place for low-income seniors: Living at the intersection of multiple identities, positionalities, and oppressions. In O. Hankivsky & J. Jordan-Zachery (Eds.), *The Palgrave handbook of intersectionality in public policy* (pp. 641–664). Cham: Palgrave Macmillan.

Sixsmith, J., Fang, M. L., Woolrych, R., Canham, S. L., Battersby, L., & Sixsmith, A. (2017). Ageing well in the right place: partnership working with older people. *Working with Older People, 21*(1), 40–48.

Chapter 8
Learning Activity: Taking the Guesswork Out of Stakeholders—Creating an Actor Model

Andrew Sixsmith

The Challenge

Effective transdisciplinary working requires the close involvement of stakeholder groups in each step of the research process (Boger et al., 2017). Stakeholders are all of the people or groups who have a viewpoint or perspective on the business, service, or issue under consideration. But typically, identifying who the stakeholders are, and what their roles are, is done in an unsystematic and opportunistic way. How do you know who should be around the table and what their particular interest and perspective might be? The stakeholder *landscape* is probably a lot more complex than first appears. For example, in a health care setting, such as a hospital or residential facility, you will have patients, family caregivers, nurses, health professionals, physicians, care assistants, support staff (e.g., cleaners and kitchen staff), as well as middle and senior management. In a for-profit organization, you may have owners, staff, and/or a board of directors. Without a systematic approach to identifying stakeholders, you may fail to get the necessary expertise into your project where and when it is needed. At best, this means failing to capture the richness of perspectives that comprise the stakeholder landscape. At worst, your project will present a partial and perhaps distorted set of findings.

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Overview of the Activity

One systematic way of identifying stakeholders and their roles is to create a stakeholder expertise map or *Actor Model* (Lunn, Sixsmith, Lindsay, & Vaarama, 2003). The Actor Model (see template) is basically a simple table that contains a comprehensive list of stakeholder types, the specific stakeholder, the role, and the particular goals within the health care setting. For example, in a long-term care setting you may find:

- Stakeholder Type: Client.
- Stakeholder: Patient/resident.
- Role: Consumer/recipient of the services that are provided. They may directly pay for services or may be in receipt of services organized and paid for by a third-party care coordinator and financier.
- Goals: To feel safe and secure, to get help with activities of daily living, feel at home, have activities and social engagement.

The aim of this activity is to build an actor model of all the stakeholders involved within the context of a health-related project, organization, or intervention that you are familiar with.

Doing the Activity

This activity is best done in a group, but can be done individually. Use the template to create your actor model:

- Make a list of all the relevant stakeholders you can think of.
- Create simple descriptions of their expertise, roles, and goals.
- Organize your stakeholders into broader stakeholder types.
- Read through and critically evaluate your actor model (on your own or with another person with expertise in the area). Consider if there are any stakeholder groups missing? Are the key roles identified? What are the underlying assumptions and implications of the labeling and descriptions in your model?
- Add in any new stakeholders and their roles and goals.
- Reflect on the process, is your final actor model what you expected, or is it more/less detailed or complex (perhaps discuss with others from outside your group)?
- What are the implications for your own research?

The final actor model produced is very much dependent on the particular problem you are addressing in the research. However, in the spirit of transdisciplinary working, it should be something that is jointly created and refined by the stakeholders involved.

At first, the model is likely to be incomplete, but it will serve as a basis for bringing together an initial stakeholder group. Discussing the model with stakeholders will help you to expand the constituency of your group.

The actor model should be revisited and refined as the research progresses; e.g., as you bring in further stakeholders and learn more about their roles and goals, your stakeholders may be broken down into more granular levels. You may also discover a new class or actor type that you had not thought of previously.

The actor model can be seen as a research output in its own right. It will provide you with a crucial starting point for understanding how a new health care intervention or product might be of value, as well as highlighting possible opportunities or threats for potential solutions.

Learning Outcomes
After doing this activity, you will expect the following outcomes:

- Have a better awareness of the potential complexity of the stakeholder *landscape*.
- Have a tool for systematically identifying stakeholders that are relevant to your project.
- Have a methodology for describing their roles and goals.

Learning Resources
A more detailed overview of this approach can be found in Lunn et al. (2003).

Supporting Materials
See Table 8.1.

Table 8.1 Actor model

Stakeholder type	Stakeholder	Role	Expertise	Goals
	X			
	Y			
	Z			
	Etc.			

References

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., Mihailidis, A., … Martin, S. (2017). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490. https://doi.org/10.3109/17483107.2016.1151953

Lunn, K., Sixsmith, A., Lindsay, A., & Vaarama, M. (2003). Traceability in requirements through process modelling, applied to social care applications. *Information and Software Technology, 45*(15), 1045–1052.

Chapter 9
Working Together as a Transdisciplinary Team

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The Challenge

Increasingly, researchers are working in teams with academics from other disciplines alongside stakeholders and partners (e.g., consumers, patients, caregivers, industry and financers, policy makers) from different sectors. This is especially true in large-scale and complex projects where the focus is on developing real-world solutions. For example, developing a new health technology might involve clinicians, social scientists, and engineers collaborating closely with industry partners and potential users of the technology. While large collaborative projects are becoming increasingly the norm, working across disciplines and sectors can be challenging. Challenges might include poor communication, lack of respect between individuals and across groups, limited awareness of the ideas and situations of different team members, personality clashes, and so on. These can lead to difficult working practices and failure to deliver on the project objectives and to deadlines. Without truly meaningful collaboration, the team and the project may miss out on the opportunity to widen their thinking and to work constructively to develop new ideas and solutions. Building on the principles of transdisciplinary working (see Chap. 4, "Introduction to Transdisciplinary Working"), this chapter outlines some

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key ideas that can help transdisciplinary (interdisciplinary and cross-sectoral) teams to work together:

- Negotiating terms of reference.
- Resolving conflict.
- Collaborating on decision-making.
- Reducing power inequalities and building rapport.

Key Ideas

Negotiating Terms of Reference

The aims, objectives, and vision of the project need to be well understood across the team. As well, roles, rules, responsibilities, and levels of commitment need to be explicitly negotiated. The development of a partnership map (mapping skills and expertise to project requirements) will help to clarify why the partnership has been formed and who has expertise and in what areas. This should make it clear to everyone that all the team members are there because they are necessary and valued in the project. Effective teams ensure that opportunities arise for partners to use, develop, and share their expertise to progress the project while recognizing that different types of expertise may be required at different project stages. For example, involving older people in technology design projects could engage them in research decision-making, data analysis, and/or dissemination practices where this is relevant and desired, alongside their input into design ideas. How partners are involved in the project will be a matter of agreement across the project team, an agreement that should be revisited as the project progresses. Some partners may be comfortable as co-investigators, others as collaborators, distant partners, or members of advisory or reference groups. At this point, it is useful to co-produce a Terms of Reference (ToR) document across the partnership. A Terms of Reference document outlines the organization, purpose, and structure of the project and identifies the ways people can contribute and how knowledge flows around the project (Jones & Wells, 2007). See Box 9.1 for an example of items typically covered in a Terms of Reference document. Revisiting such a document and keeping it up-to-date is necessary if it is to work well to reflect partner expectations and provide shared understandings about how people can work effectively together.

Box 9.1 Terms of Reference Document
A Terms of Reference (ToR) is the *Constitution* of the group or team. Initial ideas about the group are written down in a ToR document that is signed by all members of the research team and partnership group. The ToR should be revisited several times during the project to ensure they are still fit for purpose to guide the project. It can contain the following:

(continued)

Box 9.1 (continued)

- The purpose of the group (including the aims and objectives of the project and the group).
- The membership of the group (consider diversity) and roles available in it (such as division of roles, advisory, project guidance, involvement in project planning, development and implementation, data collection, etc.)
- Rights and responsibilities in relation to the group (entering and exiting the group, briefing and debriefing, and feedback loops).
- The structure of the group: number of members and frequency, length, and venue for meetings.
- The organization of the group/ways of working: style of business, social events, business planning, administrator, contact details, and creation of agendas.
- Communications: forms of communication (email, hard copy, telephone, social media), type of communication (face-to-face, virtual), frequency of communication.
- Training and support requirements (for researchers and research partners).
- Sharing of information and resources (data handling, confidentiality issues).
- Terms of Reference review (how often, who will do it, what will it involve).

Resolving Conflict

Having a clear and agreed upon policy for resolving conflicts of interest will also be an important part of building open relationships across a project. Disagreements are common in transdisciplinary working teams as partners come from different backgrounds and sectors and can have different work-related values and practices. If there is a clear process for conflict resolution and if disagreements are dealt with respectfully through a known and acceptable process, they can lead to improved and more trusting relationships and rapport once a collective resolution is achieved. Developing or adopting agreed on conflict resolution processes and practices, with designated team members responsible for putting these into action, minimizes the chance of difficult personal animosities derailing project outcomes. Acknowledging that conflict exists, and encouraging respectful communication styles and discussion, as opposed to silence (when a conflict is unacknowledged), penance, and/or censorship, is at the heart of conflict resolution (Orozco & Cole, 2008; Polk, 2015). Preventing conflictual situations is obviously better than dealing with conflicts when they arise. Here, it may be helpful to explicitly recognize differences in core organizational cultures (e.g., talk about and expose these), create clear expectations regarding which team member is involved in which activities and why, and identify workload management challenges (and potential mitigation strategies). To avoid authorship and/or *ideas ownership* disagreements, collectively decide (as early as possible) on a knowledge mobilization strategy and publications policy for the project, clarifying that writing or presentation roles, responsibilities, and the author order are dependent on level of interest and active contribution. Early development of the knowledge mobilization and/or publications policy is valuable for preventing authorship disagreements (including ways in which lead authors are chosen, how contributions are assessed, procedures for establishing author order, etc.). For commercial products and other innovations, the development of an intellectual property (IP) agreement early on, in consultation with persons with legal expertise, is advisable (Nierse, Schipper, Van Zadelhoff, Van de Griendt, & Abma, 2012). This issue is further complicated when different institutional policies need to be reflected in IP agreements. Dealing with IP is covered in more detail in Chap. 45. Finally, projects that recognize, reward, and/or celebrate the successes of team members (including administrative staff, students, and junior researchers) tend to be less conflictual and more productive.

Collaborative Decision-Making

In transdisciplinary working, it is common practice that all project stakeholders and partners are included in project decision-making. Good communication is an essential part of this process (see Chap. 6, "Building Partnerships and Co-creating with Diverse Stakeholders"). Different stakeholders hold varying levels of knowledge and often use discipline-specific languages or professional jargon to communicate. This can cause confusion when the same word is interpreted differently across disciplinary or sectoral boundaries, e.g., the word *critical* can mean very different things to an academic (*analytical*), a technician (*important*), or a clinician (*grave* or *life-threatening*). Taking time to discuss, share, and enjoy language differences within the team can prevent miscommunications and ultimately ensure that all team members have the necessary information to actively and effectively communicate and share decision-making. For instance, hold project team working meetings with all stakeholders to include them in discussing, developing, and determining the study design, roles (e.g., participants as co-researchers), and recruitment strategies, data analysis techniques and processes (e.g., involving co-analysis of data with partners and participants), manuscript and report preparation (e.g., co-authorship with both academic and nonacademic partners), and knowledge translation activities (e.g., including knowledge mobilization and commercialization).

Shared decision-making requires openness and transparency where different perspectives can be aired and discussed and agreements acknowledged and actioned. When people feel listened to, they are more likely to accept decisions made.

Reducing Power Inequalities and Building Rapport

Power dynamics within teams structure the way that team members work together and, at times, can be difficult to negotiate. Unacknowledged power dynamics may silence some team members' voices (e.g., experiential stakeholders such as children or carers) while prioritizing the voices of others (e.g., experienced researchers). In transdisciplinary working teams, all voices are considered to be important, and all have the potential to impact project development and outcomes. This reflects the fact that members are part of the project team because they have expertise and skills that are relevant to the effective carrying out of the project. Deciding whose voice is most valuable at different points in the project can be a challenging, but useful, team activity. For example, although patients' (as stakeholders or partners in a project) experiences can be powerful motivators for the development of solutions to health issues, they may have less value in determining decisions about statistical data analysis (unless that is their area of expertise as well!). To promote a more open and equitable distribution of power right at the project outset, it is advisable to discuss power dynamics and develop a plan to address potential challenges. Bringing power differentials into the open and recognizing their potential impact on the project can be achieved using an *appreciative inquiry* approach (Whitney & Trosten-Bloom, 2010).

Appreciative inquiry suggests that "human organizing and change at its best is a relational process of inquiry grounded in affirmation and appreciation" (Whitney & Trosten-Bloom, 2010, p. 1). Building rapport based on the principles of appreciative inquiry (see Box 9.2) can help all team members to understand and support each other within the project. Trust and openness to each other's ideas develops through discussion and inquiry sessions, which encourages team members to shift their attention and action away from differences, problems, and issues and to move toward appreciating individual and group knowledge as useful for the development of new ideas and productive possibilities for the future (Whitney & Trosten-Bloom, 2010).

Box 9.2 Appreciative Inquiry in Action
In an arts and mental health project—the Pathways Project—a team of artists, psychologists, and mental health professionals came together to explore how a community-based arts project could support people with mental health problems (Sixsmith & Kagan, 2005). Several projects were identified, and methods were developed by the team psychologists to measure their *effectiveness*. It quickly became apparent that the artists felt that this measurement seemed judgmental, while the mental health professionals felt that their expertise had been ignored. Project meetings were confrontational, destructive, and defensive. To promote more positive working relationships, an *appreciative inquiry* (AI) facilitator collaborated with the team to design a workshop that used artistic team building exercises focused on arts for mental

(continued)

Box 9.2 (continued)
health. The session was productive and encouraged participants to view the problem through alternative, positive *lenses*, including measurement, psychological theory, art, and mental health. This meant that participants needed to ask each other for their expertise and guidance in order to adopt the alternative perspectives. This helped to bring the team together. Measurement issues were addressed; in fact, many of the original measuring instruments were retained with buy-in from the artists, and new ones added that focused on a wider range of mental health issues. The impact of the AI workshop was immense: co-creation was achieved; integrating different knowledge bases enabled new understandings to develop; and methods were adjusted to reflect team sensitivities.

Understanding how different team members can be equitably involved also requires active listening to determine the value of their contributions. Active listening is a skill that can be developed at both an individual and group level. For instance, *listening for directions* is an exercise frequently used in community mobilization to generate opportunities for *listening to* and *appreciating* diverse perspectives, identifying commonalities (e.g., problem areas, challenges), and achieving consensus on goals and solutions. Such listening exercises can help address misunderstandings, open up communication for additional explanations or information, and provide opportunities to help partners understand specific disciplinary or sectoral language (Krumer-Nevo, 2005).

Transdisciplinary Team Working and the Product Innovation Pathway Model

Transdisciplinary working is neither a standard nor a linear process nor a set of activities that can easily be fitted into a simple how-to since it is a process that is adjusted to each specific research context. However, it is possible to identify some key activities of transdisciplinary working that are linked to the Product Innovation Pathway (PIP) model (Table 9.1).

Finding Resources

- For examples of Terms of Reference documents, see State Government Victoria (n.d.), Department of education and early childhood development. *Terms of reference template*, https://www.education.vic.gov.au/Documents/school/principals/management/networktermsreftemp.pdf.
- For more information about appreciative inquiry, refer to
  Cooperrider, D. L., & Srivastva, S. (1987). Appreciative inquiry in organizational life. *Research in Organizational Change and Development, 1*, 129–169. https://

Table 9.1 Product Innovation Pathway (PIP) model—transdisciplinary team working

PIP stage	PIP description	Key activities*
1	Innovative ideas	Formalize expectations (time commitments, roles, etc.) in a term of reference document; develop communications protocol and conflict resolution strategy; emphasize sharing ideas and creating shared vision, aims, and objectives
2	Planning	Plan to create co-ownership of the project. Involve all project partners including lay population representatives with experiential knowledge. Ensure inclusive and frequent communications; develop a publications policy and intellectual property document. Attend to power inequities by discussing power issues and contributions to decision-making. Promote active listening through listening exercises. Host cross-project learning events (e.g., action learning sets, knowledge seminars, and/or master classes). Run appreciative inquiry workshops to develop project co-ownership ethos
3	Development	Adopt a reflective and action-oriented perspective that values continual critical assessment and active listening. Encourage individual and group reflexivity such as discussions on the nature of project working relationships, revisiting and analyzing project process dynamics, outcomes, and outputs
4	Testing in real-world environment	Alongside development actions, adopt an iterative approach to monitoring team progress and seek diverse perspectives on project success and challenges in real-world settings
5	Outcomes and impact	Translate project outputs and outcomes into real-world impacts. Track impacts of the project via public involvement, through commercialization plans (where relevant) and knowledge mobilization plans. Encourage two-way communications between the project team and external audiences

www.centerforappreciativeinquiry.net/wp-content/uploads/2012/05/APPRECIATIVE_INQUIRY_IN_Orgnizational_life.pdf.

Final Messages

Working as a team in a transdisciplinary working project requires explicit attention to developing working practices that cross disciplines and sectors partnerships to engage in meaningful dialogue and co-production of knowledge and real-world outcomes:

- Transdisciplinary working is not a method or an activity; rather it is an approach or mind-set to create innovative solutions to real-world complex problems.
- Addressing conflictual issues and power inequalities is not an inherent team working process and requires conscious effort to ensure that all partners and stakeholders are active and decision-making members of the team.
- Transdisciplinary working requires substantial effort and commitment to focus not just on the project but on team working practices as well if decision-making is to be an equitable experience for all.

References

Jones, L., & Wells, K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *Journal of the American Medical Association, 297*(4), 407–410. https://doi.org/10.1001/jama.297.4.407

Krumer-Nevo, M. (2005). Listening to 'life knowledge': A new research direction in poverty studies. *International Journal of Social Welfare, 14*(2), 99–106.

Nierse, C. J., Schipper, K., Van Zadelhoff, E., Van de Griendt, J., & Abma, T. A. (2012). Collaboration and co-ownership in research: Dynamics and dialogues between patient research partners and professional researchers in a research team. *Health Expectations, 15*(3), 242–254. https://doi.org/10.1111/j.1369-7625.2011.00661.x

Orozco, F., & Cole, D. C. (2008). Development of transdisciplinarity among students placed with a sustainability for health research project. *EcoHealth, 5*(4), 491–503.

Polk, M. (2015). Transdisciplinary co-production: Designing and testing a transdisciplinary research framework for societal problem solving. *Futures, 65*, 110–122. https://doi.org/10.1016/j.futures.2014.11.001

Sixsmith, J., & Kagan, C. (2005). *Arts for mental health*. Final report. Research Institute for Health and Social Change. Manchester: Manchester Metropolitan University.

Whitney, D. D., & Trosten-Bloom, A. (2010). *The power of appreciative inquiry: A practical guide to positive change* (2nd ed.). San Francisco: Berrett-Koehler Publishers.

Chapter 10
Learning Activity: Essentials of Teamwork

Euson Yeung

Teamwork

Effective teamwork is an essential ingredient in all fields of research. We all desire to be involved in research projects where communication between team members is consistently clear, project timelines are always met, and the quality of work regularly exceeds our expectations. But more often than not, our experience working within teams is less than ideal. It is not surprising that teams sometimes fall short of these ideals because effective teamwork requires us to continually pay attention to and spend time on the process of team development. Rarely does good teamwork just happen on its own.

Attending to a team's process goes beyond ice-breaker activities that acquaint team members with each other. Rather, *effective* teamwork requires team members to value and move through different steps of the team development process as outlined below (see photo) (Bonebright, 2010; Tuckman, 1965):

- **Forming**: The team negotiates and establishes goals, becomes familiar with the strengths and roles of team members, sets clear timelines, and determines a clear decision-making process.
- **Storming**: The team encounters common challenges that are inevitably part of the team process.
- **Norming**: The team begins to resolve challenges as members develop mutual respect, recognizes team members' strengths, appreciates differences, and provides constructive feedback. There may be considerable time spent moving back and forth between the storming and norming steps as new issues and tasks arise.

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- **Performing**: The team is achieving what it set out to accomplish.
- **Adjourning**: The team may disband as the project is completed or draws to a close.

All teams move through the steps of development at varying rates, and each step requires team members to be attentive to different group processes.

Activity

This is an experiential learning activity that will help teams value and understand the initial step of team development: *forming*. The purpose of this learning activity is to demonstrate the importance of outlining *ground rules* for team functioning at the outset of any research project. Specifying and structuring the components of the *forming* step through this learning activity will make it clear why and how teams can (1) establish common goal(s), (2) clarify roles and communication strategies, (3) determine a clear decision-making process, and (4) build mutual trust.

Doing the Activity

Activity: "Team Pen"

Objectives:
- To help participants appreciate the importance of the *forming* step of team development.
- To equip participants with tools to progress through the *forming* step of team development.

Description—Part I:
- Divide participants into teams of 5–8 individuals. Ask 2–3 members of each team to put on a blindfold.
- Each team is given a large piece of paper to draw on and a pen and/or marker that has a number of strings or rope of equal lengths attached to it (one string or rope for each member of the team).
- Without giving further instructions, ask each team to draw a star on the piece of paper in front of them. Assign a time limit for this activity (e.g., 2 min).

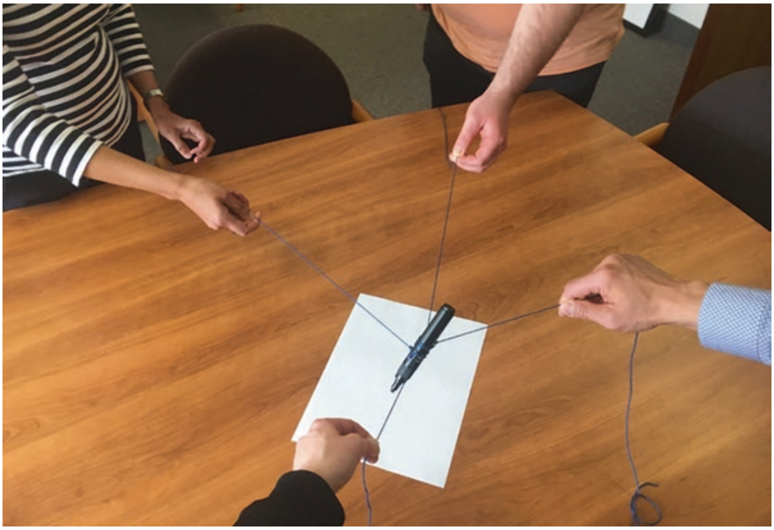

Photo credit Euson Yeung

Debrief no. 1: Ask open-ended questions that help participants understand the essential components of the *forming* step of team development. Sample questions include:

- What did you notice about the group process that facilitated "good" teamwork? (*invite general comments*).
- What kind of star did you draw? How did you know what kind of star to draw? (*establish common goals)*.
- What role did you take up during the activity? Who took the lead? What could be done to make it more clear who is doing what? (*clarify roles*).
- What was the communication like during the activity? How could communication be improved for this task? (*establish communication strategies*).
- What was the decision-making process like? How did you end up making decisions? What would have improved the decision-making process? (*determine a decision-making process*).
- For those who were blindfolded, what was the experience of working in your team like for you? (*establish communication strategies, develop trust in other team members*).

Part II:

- Give teams 5 min to discuss their approach to completing the same activity.
- Then ask each team to draw a star on another piece of paper in the same manner as in the first attempt. Assign a time limit for this second attempt (e.g., 2 min).

Debrief no. 2: Ask open-ended questions that help participants understand the value of attending to the *forming* step of team development. Sample questions include:

- What was different about your team's second attempt on the same activity? What remained the same? Why?
- How clear was the goal of the task among everyone on your team? Why do you think that is?
- How clear were the roles that team members took on?
- What was the communication like between team members?
- What are key lessons you will take away for developing your own research teams?

Learning Outcomes
After participating in this activity, you will expect the following outcomes:

- Understand how working on team process will improve the function of teams.
- Be able to define the components of the *forming* step of team development.
- Be able to help a team progress through the forming step of team development.

Learning Resources
- Tuckman, B. (1965). Developmental sequence in small groups. *Psychological Bulletin, 63*(6), 384–399. https://doi.org/10.1037/h0022100. PMID 14314073. Reprinted with permission in Group Facilitation, Spring, 2001.
- This resource provides an overview of proposed sequential steps of group development, to situate the aforementioned activity within the entire small group development process.
- Haas, M., & Mortensen, M. (2016, June). The secrets of great teamwork. *Harvard Business Review*, June, 70–76. https://hbr.org/2016/06/the-secrets-of-great-teamwork.
- This resource offers an example of the important role that contextual factors play in the small group development process.

References

Bonebright, D. A. (2010). 40 years of storming: A historical review of Tuckman's model of small group development. *Human Resource Development International, 13*(1), 111–120.
Tuckman, B. W. (1965). Developmental sequence in small groups. *Psychological Bulletin, 65*(6), 384–399.

Chapter 11
Engaging *Hard-to-Reach*, *Hidden*, and *Seldom-Heard* Populations in Research

Shannon Freeman, Kelly Skinner, Laura Middleton, Beibei Xiong, and Mei Lan Fang

The Challenge

It is imperative that researchers consult and include members of their true target group in research. This is especially important when the target group is challenging to engage. Researchers should ensure that findings are applicable to contexts outside of the study situation (for qualitative research) or their participants are representative (for quantitative research) of the target group so that the results may be generalizable to others outside of the research study. It is difficult to connect with some groups of people who (1) are hard to find, (2) who do not wish to be found, or (3) who are not typically recruited in research using traditionally planned recruitment methods. These groups can also be referred to as *hard-to-reach* (i.e., hard to find), *hidden populations* (i.e., those who do not wish to be found), and *seldom-*

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heard (i.e., those who are often not included in recruitment). This chapter describes similarities and differences between these groups and offers strategies to recognize, address, and overcome challenges and to support inclusion of these groups in research. The importance of developing meaningful and authentic relationships with these participants is addressed in a separate chapter.

Key areas of focus in this chapter are:

- Identifying populations.
- Making initial contact.
- Addressing challenges to recruitment.
- Addressing challenges to sampling.
- Addressing challenges to retention.

Key Issues

Identifying Populations

A target group is defined by a shared characteristic that can include social, geographical, clinical, or other criteria. *Hard-to-reach* populations are groups of persons who are difficult to find and often even more challenging to engage. Hard-to-reach populations may include vulnerable populations, such as persons with low-socioeconomic status, victims of abuse and trauma survivors, persons with complex health impairments or those nearing end of life, and populations at higher risk of discrimination or stigma (e.g., opioid substance users, members of the LBGTQ+ (lesbian, gay, bisexual, transgender, queer, and questioning) community, Indigenous peoples).

Hidden populations are also difficult to access, but they differ from hard-to-reach populations. Persons belonging to a hidden population often highly value their privacy and may purposefully conceal their identity from researchers. As such, it is difficult for researchers to know how to define membership to the target group and establish appropriate inclusion criteria for the study sample. Researchers may not be able to accurately estimate prevalence of the target population. Often, but not always, hidden populations include individuals who engage in socially less desired, undesired, and at times illegal behaviors. Members of hidden populations may expect to be stigmatized should their membership to the hidden population be made known. Members of hidden populations may refuse to participate in a study, avoid responding to certain questions in surveys and interviews, and provide false responses or lie intentionally to researchers so that their membership in the hidden population remains protected. Examples of hidden populations can include victims of elder abuse, childhood abuse survivors, or athletes who use steroids.

Hidden populations and *hard-to-reach* populations may also be considered *seldom-heard* populations, but not all *seldom-heard* populations are hidden or hard to reach. *Seldom-heard* populations can also include people who are identifiable and known to researchers, such as children with life-limiting conditions, persons with intellectual disabilities, and persons with dementia. However, barriers exist to inclusion and participation in research. As such, the ability for their voices to be heard can be limited. This can also occur due to the sensitive subject matter that unites the population where there may be increased stigma or risk to the person or others if they were to speak about their lived experience.

Making Initial Contact

When conducting research, researchers can begin by asking themselves key questions such as:

- Who am I trying to listen to and gather information from?
- Where can I find them?
- Who might know where to find them?
- How can I find and make initial contact with them?

It is necessary to identify the population that the researcher wishes to include early on. A plan or strategy for making contact with the population that is feasible (i.e., meets fiscal and time constraints) must be developed. The researcher needs to reflect on specific barriers to finding the population before the researcher can build relationships and engage the population for recruitment of participants. Once a relationship is established, the researcher should consider strategies to support continued engagement with the population and ensure that the relationship either continues or ends in a positive, respectful, and non-damaging manner.

The first step a researcher needs to overcome is their own discomfort about engaging with these populations. Making the first initial contact can be challenging but is worth the effort, regardless of whether the effort is successful. Researchers engaging in work with new populations may consider seeking mentorship and guidance from other researchers who have experience with the same or similar populations. Practical tips from other researchers may provide useful insights and population-specific strategies to mitigate challenges and identify existing oversights in reaching and including these populations. Connections may begin with access through informal routes including word of mouth or through a gatekeeper. Strategies to get the word out may include putting up posters in a place that your population may see, posting recruitment notices on Internet mailing lists or in chat groups, spreading the word through news media, and/or posting of ads on social media sites. Researchers may consider creating a webpage or viral video and distribute it through social media to capture interest of others to encourage them to make a connection. Another avenue is to partner with organizations that provide services for these populations. Researchers may need to employ multiple methods, and if one method does not seem to work, the researcher must be flexible to adjust their strategy as needed. The researcher must also provide information on how members of the population of interest can contact the researcher. A simple blind email may not suffice. Researchers may consider advertising about their research study on a social media platform, which the researcher believes potential participants may use. The researcher can then identify key characteristics or interests that potential participants may use to identify whose feeds the ads should be posted. For example, people who like a certain organization, product, or blog post may also be more likely to be the potential participants the researcher is seeking. If the first contact is identified, researchers may strategically seek out opportunities to connect at public events, such as following a talk at a conference and attendance at a public meeting or public rally. Yet often some populations may not have phones or access to the Internet or to email. This is where word of mouth from organizations which work with these populations or from recruited participants becomes an important method for recruitment. For example, the *Our Health Counts* report was able to fill a critical gap in data for Toronto's urban Indigenous community by using respondent-driven sampling methods. Using these methods, the researchers found that Toronto's Indigenous population is approximately two to four times larger than what Statistics Canada has reported from the census (Seventh Generation Midwives and Well Living House, 2018).

Recruitment

Strategies for recruitment for persons who are hard to reach may not be the same as strategies to connect with those who are hidden. For hard-to-reach populations, we know the criteria that define our target group, upon which researchers may design their recruitment strategy. Researchers may consider a variety of strategies when trying to recruit hard-to-reach and hidden populations. Numerous barriers to recruitment exist including:

- Mistrust of researchers.
- Research participation fatigue due to increased requests for research participation.
- Fear that research may cause harm, increase stigma, or lead to exploitation.
- Lack of perceived benefits from participation.
- Lack of health literacy and/or education of study purpose and procedures.
- Fear of loss of anonymity.
- Fear of repercussions for disclosure (e.g., fear of legal action if disclosing illegal behaviors) (Bonevski et al., 2014).

Early in the research process, researchers may identify persons who engage with the target group, whether by advising or otherwise influencing the target population (e.g., community leaders, physicians, teachers, support group facilitators). For example, for persons with a complex health condition, this person may be a doctor or allied healthcare professional. For persons nearing end of life, this may be a community social worker or spiritual leader. It may be helpful for researchers to consult with these leaders in advance to seek their advice in developing a recruitment strategy or to request assistance in recruitment of study participants (e.g., through a clinic mailing list or by sharing of a recruitment pamphlet). Another strategy is to connect with community contacts such as peers of participants or known recruiters who have already developed relationships within the community. Before connecting with participants and community contacts, researchers should consider creating a safety protocol or guidelines on how to be safe when undertaking community consultation and fieldwork activities.

Many funding bodies such as the Canadian Institutes for Health Research (CIHR) promote patient-oriented research (http://www.cihr-irsc.gc.ca/e/41204.html) or community-engaged research (i.e., with Indigenous populations and communities) where a patient or community is engaged as a research partner at all steps, from the initial steps of identifying research questions and goals, through to dissemination of research findings (CIHR, 2017). Patient-oriented and community-engaged research aims to decrease the research to practice gap or the knowledge to action gap by supporting researchers to conduct research, which is relevant to the real-world needs of those for whom the project is developed. Community contacts engaged with the researcher and/or the research project may be able to identify others who also recognize the value.

Researchers need to recognize and understand the power dynamics involved in participant recruitment and address any potential conflicts of interest. For example, it may be possible for a physician to refer terminally ill patients to a study or for a social worker to promote a new research study examining effectiveness of a bereavement support group. However, there may be unintended consequences. At times, persons with a complex medical condition will follow the advice of a physician to participate in a research trial as they consider the recommendation to join the trial as clinical advice. It is important that during recruitment, participants recognize that they have a choice and that their voice is valued.

Other strategies to overcome challenges to participant recruitment include sensitive wording (e.g., using *study* or *project* instead of *investigation*, or using *discussion* or *conversation* instead of *interview*), use of personal hand written names and addresses on envelopes instead of printed labels, emphasizing potential benefits at community events, two-step recruitment strategy (e.g., first offer brief survey with small incentive followed by recruitment to a second more in-depth intervention or trial with increased incentive), and sharing of culturally relevant recruitment and education materials (Bonevski et al., 2014).

Retention

Once researchers are successful in making contact with the target population, it is beneficial to invest in the new relationship within the community. Researchers must exercise judgment and be cognizant of issues with retention and sustainability when identifying the community partners and leaders to support research moving forward. Once a contact is made, researchers should continue to develop and expand relationships within the community of focus. Commonly, key stakeholders and gatekeepers may engage and then disengage in activities with or without notice. When working with First Nations communities, this may be a common experience if working with elected leadership members such as Chief and Council who may be elected by the community every 2–3 years. This could also occur if partnering with a nonprofit community organization with significant turnover in staff or run by a volunteer board where members may have fixed terms. If a researcher is partnering with community leaders and/or volunteers, then sustaining project momentum and partner engagement can be challenging. In these cases, researchers who have not developed extensive relationships within the community will find it difficult to sustain research projects and will often need to start over with community engagement activities to identify new key stakeholders.

Box 11.1 Keeping People Engaged Even When Means to Keep Them Engaged May Change
Keeping community members and participants engaged can be a challenging process and often requires creative methods when conducting research. One approach to facilitate engagement when working with a diverse group, of often seldom heard groups, is via participatory mapping—a map-making process that aims to create a visible display of people, places, and experiences (Corbett, 2009). This collaborative approach is action-oriented and is used to "enable local people to share, enhance and analyze their knowledge of life and conditions to plan and act" (Chambers, 1994, p. 953). Participatory mapping can be used to generate understandings that people construct concerning the resources, services, feelings, and experiences of their local community (Fang et al., 2016). One distinctive aspect of community mapping is that it begins with, and prioritizes and values local knowledge, disrupting hierarchical power relations between participants and researchers to equalize the knowledge space between them (see Wood, Froh, & Geraghty, 2010).

Researchers must also consider how to keep participants engaged. Strategies to keep participants engaged may change over time as participants' age, their diseases progress, and participant circumstances change (Box 11.1). Researchers must remain flexible and responsive to the needs of the participants. Researchers should gauge the participant risk levels and implement retention strategies accordingly. Zweben, Fucito, and O'Malley (2009) grouped key strategies to participant recruitment and retention into two categories employing (1) routine, and (2) non-routine strategies. Researchers can first use routine strategies as described in Box 11.2.

Box 11.2 Maintaining Research Participant Engagement Using "Routine" Strategies

It is important to foster a welcoming, respectful, and nonjudgmental research environment to engage participants in co-creation and partnership in the research activities. Provide education about the expected role of participants including explaining information about study protocol, duration, and expectations about follow-up so that participants feel comfortable and included in the research process. Address any anticipated barriers to participation (e.g., child care, housing, transportation, employment conflicts, etc.) through open communication with participants and flexibility in study protocol to be responsive to participant need. Researchers should carefully consider frequency and mode of scheduling reminders including letters, phone calls, and rapid follow-up at time of study design and integrate these strategies into the study protocol. Provide incentives for continued participation and engagement in study activities so that participants feel appreciated. This could include financial incentives for completion of assessments, thank you letters sent on participant's birthdays or major holidays, recognition of participants at local events, or waiving of fees for services. Lastly, researchers should implement an efficient tracking system to follow participants over time and maintain ongoing contact (see Zweben et al., 2009).

If participants do not respond to the existing research protocol and the routine strategies fail to produce the expected results, researchers then may consider non-routine strategies as described in Box 11.3. Often *hard-to-reach* and *hidden populations* require researchers to employ non-routine strategies to respond to needs of participants who may miss follow-up sessions, are reluctant to book follow-up sessions, or express intent to drop out of the study.

Box 11.3 Maintaining Research Participant Engagement Using *Non-routine* Strategies

At the start, identify participants who are at high risk of drop out and/or at high risk for nonadherence to the study protocol and ensure consistent education of research staff so they are knowledgeable on how to identify participants who are at high risk of drop out and equipped with a variety of means to follow-up with at-risk participants. Conducting an adherence assessment in partnership with the participant can help encourage commitment to the study. Researchers should make efforts to connect in-person or by phone with participants at risk of drop out to gather information on the barriers perceived by participants affecting their abilities to participate. When researchers cannot connect in person, follow-up text messages and letters can also be sent to encourage continued participation. It is also useful to develop a participant-

(continued)

Box 11.3 (continued)
specific mitigation strategy that includes having up-to-date phone numbers and addresses of participants, designing flexible meeting times, setting convenient locations for meet ups, and arranging to go to a participant's location of choice to collect data. Researchers can work with participants to negotiate new ways to address barriers to participation and support continued engagement. A variety of options may be available depending on the person-specific needs of the participant (see Zweben et al., 2009).

Researchers need to clearly communicate to participants "what's in it for them" beyond just the benefits of participating in a research study. It is important to communicate how the findings from the study may be used to inform others. Successful longitudinal studies often prioritize developing participant's sense of pride in their participation in the study.

Sampling

Researchers must carefully consider which type of sampling strategy is most likely to be effective, feasible, and cost-efficient means to capture the population of focus. Sampling strategies should respond to the specific characteristics of the target group. There is no one-size-fits-all strategy that will be effective for all populations. Simultaneously, even within groups, there may still be great diversity. For example, persons with dementia include those who are minimally impaired in early-stage disease and those who are uncommunicative and immobile in late-stage disease. They can have young-onset Alzheimer's disease at age 30 years to more typical onset in older age. Some people with dementia remain very socially active, while others are withdrawn due to choice or due to poor access to social support and transportation. The sampling strategy should carefully consider the target population and adapt the research approach to employ behaviors that are likely to be effective for all key subgroups.

In a systematic review, Bonevski et al. (2014) note that when probability recruitment strategies are ineffective, researchers should consider employing non-probability sampling options. They further describe a variety of non-probability sampling options ranging from snowball/social network and respondent-driven recruitment to adaptive sampling and oversampling of low-prevalence population subgroups (Bonevski et al., 2014). With each sampling strategy, researchers must carefully consider potential trade-offs (e.g., increasing sample size may improve representativeness, but may also increase costs of study and time required to recruit participants). Considering the advantages and disadvantages of each sampling method may support researchers to select a strategy that maximizes participant recruitment and involvement in the study and which is also feasible within the study budget and timelines.

Researchers may consider convenience sampling and purposive sampling by connecting through community organizations where members of the population may attend. This may include recruitment through social agencies (e.g., partnering with a local food bank or soup kitchen when looking for persons who are financially disadvantaged). Though the sample reached through this strategy may not be representative of all members of a target population, there are advantages to this method. Recruitment through community organizations may also support researchers to build a mutually beneficial relationship as the findings from the study may then be of greater benefit if shared back with the community organization. This may lead to the opportunity for knowledge exchange and increased potential for integration of research findings to inform policy and practice (Table 11.1).

Finding Resources and Support

- Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J. & Hughes, C. (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC medical research methodology, 14*(1), 42.
- Mowatt, B., & Young, J. (2006). *Guidelines for the recruitment and retention of Aboriginal women volunteers: Handbook*. Knowledge Development Centre, Imagine Canada.
- Auerswald, C. L., Piatt, A. A., & Mirzazadeh, A. (2017). Research with disadvantaged, vulnerable and/or marginalized adolescents (Innocenti Research Brief 2017-06, Methods: Conducting research with adolescents in low-and middle-income countries, no. 4). Florence, Italy: UNICEF Office of Research-Innocenti.
- York University Human Participants Review Committee. (2008). Guidelines for Conducting Research with People who are Homeless.
- "Guidelines for conducting research with First Nations communities." First Nations Information Governance Centre (FNIGC). (2018). The First Nations principles of OCAP®. http://fnigc.ca/ocap.html.
- Snow, M. E., Tweedie, K., & Pederson, A. (2018). Heard and valued: the development of a model to meaningfully engage marginalized populations in health services planning. BMC health services research, 18(1), 1–13.
- "Recruiting older adults into research (ROAR) toolkit." https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit.

Key Messages

- In research, it can be difficult to connect with some groups of people who (1) are hard to find, (2) who do not wish to be found, or (3) who are not typically recruited to research studies using traditional recruitment methods.
- Your target group is defined by a shared characteristic that can include social, geographical, clinical, or other criteria, and it is necessary to map these out before making first contact.

Table 11.1 Product Innovation Pathway (PIP) model—engaging hard-to-find, hidden, and seldom-heard populations

PIP level	PIP description	Key activities[a]
1	Concept	Identify the population of interest • Describe target group with specific participant inclusion and exclusion characteristics • Remain flexible in expectations balancing what is desired with what is feasible
2	Planning	Design a population-specific recruitment strategy • Weigh the opportunities and challenges of feasibility, accessibility, and representativeness (non-probability vs. probability sampling) of target population • Identify the gatekeepers to the population of focus and how you may engage them to support your efforts Establish relationships • Seek guidance and input from others with experience working with these groups • Expect that development of relationships will take time and effort • Listen to and be aware of the needs of your participants
3	Development	Develop a first-line recruitment strategy • Identify mitigation strategies to adjust recruitment if the first is not sufficiently successful • Secure resources to support recruitment and retention of participants during and following the study
4	Testing in real-world environment	Initiate recruitment • Gauge the participant risk levels and implement recruitment strategies accordingly • Confirm with participants that they belong to the population from whom you are trying to recruit • Tailor and adapt your strategy following guidance and input from participants to keep participants engaged • Remain flexible and responsive to the needs of the participants
5	Outcomes and impact	Focus on participant retention • Invest resources to support retention and ongoing engagement of participants during and following the study • Regularly reassess participant risk levels and revise retention strategies according to participant needs

Note. [a]The levels on this table are iterative and not linear. Some topics may require ongoing focus and revision of strategy employed depending on the new and/or continued engagement of participants

- It is important to identify the population that the researcher wishes to include early on by developing a recruitment plan or strategy for making first contact.
- Before recruiting, it is necessary to recognize that strategies for recruiting for persons who are hard to reach may not be the same as strategies to connect with those who are hidden.
- Once initial contact is made, researchers should continue to develop and expand relationships within the community of focus.

- For sampling, researchers should carefully brainstorm a strategy that will be effective, feasible, cost-efficient, and responsive to the specific characteristics of the target group.

References

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., … Hughes, C. (2014). Reaching the hard-to-reach: A systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology, 14*(1), 42.

Canadian Institutes for Health Research. (2017). *CIHR Strategy for patient-oriented research*. http://www.cihr-irsc.gc.ca/e/41204.html.

Chambers, R. (1994). The origins and practice of participatory rural appraisal. *World Development, 22*(7), 953–969.

Corbett, J. (2009). *Good practices in participatory mapping*. Rome: International Fund for Agricultural Development.

Fang, M. L., Woolrych, R., Sixsmith, J., Canham, S., Battersby, L., & Sixsmith, A. (2016). Place-making with older persons: Establishing sense-of-place through participatory community mapping workshops. *Social Science & Medicine, 168*, 223–229.

Seventh Generation Midwives and Well Living House. (2018). *Our health counts Toronto*. http://www.welllivinghouse.com/what-we-do/projects/our-health-counts-toronto/.

Wood, A. M., Froh, J. J., & Geraghty, A. W. (2010). Gratitude and well-being: A review and theoretical integration. *Clinical Psychology Review, 30*(7), 890–905.

Zweben, A., Fucito, L. M., & O'Malley, S. S. (2009). Effective strategies for maintaining research participation in clinical trials. *Drug Information Journal, 43*(4), 459–467.

Chapter 12
Case Study 1: The Nak'azdli Lha'hutit'en Project—Creating Digital Stories with Elders and Youth in Nak'azdli First Nation

Shannon Freeman, Kelly Skinner, Jenny Martin, and Simone Hausknecht

In the community of Nak'azdli First Nation, Elders are recognized and well respected as keepers and sharers of local knowledge and oral histories. In our prior work with Elders in Nak'azdli, more than half of the Elders surveyed wished to share their wisdom, skills, stories, and knowledge, especially with younger generations (Tonkin, Freeman, Martin, Ward, & Skinner, 2018). The community identified a need to preserve the stories of their Elders for future generations. Nak'azdli community representatives collaborated with university researchers to design an intergenerational digital storytelling program aimed to engage Elders with youth in the community to capture and share the Elders' wisdom and knowledge and build the youths' skills with technology (Freeman, Martin, Nash, Hausknecht, & Skinner, 2019). The challenge was to engage the Elders, youth, and the school interested and involved in this program and to build workshop sessions that worked for everyone to participate.

A leading Elder in Nak'azdli named this the "The Lha'hutit'en Project" where Lha'hutit'en means *we work together, we help one another*. The project was co-created with an advisory committee of community and academic partners and led by the Director of the Nak'azdli Health Centre. The two key groups needed to

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engage with in this project were Elders and youth, both requiring different methods of engagement and having different needs to be able to participate. Key school and community members, knowledgeable about their community membership, drafted a list of Elders recognized as wisdom holders and dynamic storytellers who were also relatives of students or keen to mentor youth, and who would be available during the dates set for the workshop. Homeroom teachers who were enthusiastic about the project asked students in Grades 6 and 7 to participate and worked to ensure informed consent was received from parents and assent obtained from the children. Small groups of three to four students were paired with one or two Elders. Ten workshop sessions of 2.5 h each were held over a 4-week period to accommodate scheduling constraints acknowledged and communicated by the school. Elders were provided with transportation to each workshop session and were served tea and bannock by the students. The workshop sessions began with story sharing where Elders shared their stories and students asked questions and recorded the stories. No written script was created. Instead, throughout the subsequent workshops, the groups worked with the oral recordings. Students used WeVideo software to create their digital stories. Students added images and sound at key points in the stories. Elders and students worked together to edit and finalize the digital stories. Following completion of the workshop, a community showcase event was held where the students introduced their Elder storytellers, shared why the story was selected, and then showed the digital stories that had been created. To evaluate the program, focus groups were conducted with students, at mid- and end-project, and interviews with Elders and teachers (at the end of the project). Community attendees at the showcase event also completed an evaluation survey.

Ten groups of students (n = 31) and Elders (n = 13) participated in the program and each group produced a 4–7 min digital story. Students were proud of using new technology to create the stories. The students found the workshop enjoyable and had fun connecting with the Elders. Employment of an arts-based approach to learning the technology and intergenerational co-creation of the digital stories enabled all students to be engaged. Elders enjoyed sharing their stories, spending time with other Elders, and working with the students. They valued the opportunity to preserve their language and were enthusiastic about creating the digital stories as a legacy for future generations. One of the most important components of this project was a community showcase event at the school at the end of the project. At the event, Elders and youth introduced their digital stories by describing why they chose their story and what the story meant to them and then their story was shown to the audience on a big screen. Elders, students, teachers, parents, families, and community members were invited to attend the showcase and a dinner feast was provided. This was a special way for the Elders and youth to share their stories with their families and the community.

Key Messages

- Allow time to build meaningful relationships with community leaders. This may take months to years to develop trust and mutual understanding.

- Consider your target population and what unique needs they might have (e.g., transportation, scheduling constraints, a translator).
- Listen to and take direction from community leaders knowledgeable about issues facing the community and remain flexible, recognizing that the priorities of the community may change over time.

Project Details and Team This project was funded by a grant from AGE-WELL, support from the Nak'azdli Health Centre and from the Nak'albun Elementary School that covered costs for workshop facilitation, honorariums for Elders, transportation costs, technology hardware, travel costs, and the community showcase. The main collaborative relationship was between the Director of the Nak'azdli Health Centre and a researcher at the University of Northern British Columbia (UNBC). Community partners included the Mental Health and Wellbeing program at the Nak'azdli Health Centre, the Nak'azdli Whut'en, the Nak'azdli Elder Society, Nak'albun Elementary School, Nezul Be Hunuyeh Child and Family Services Society, and the Nak'azdli Youth Council. Academic partners included faculty from Simon Fraser University (SFU) and the University of Waterloo as well as trainees including a Ph.D. student from SFU experienced in digital storytelling, undergraduate and graduate students from UNBC, and medical students from the University of British Columbia.

References

Freeman, S., Martin, J., Nash, C., Hausknecht, S., & Skinner, K. (2019). Use of a digital storytelling workshop to foster development of intergenerational relationships and preserve culture with the Nak'azdli First Nation: Findings from the Nak'azdli Lha'hutit'en Project. *Canadian Journal on Aging*. https://doi.org/10.1017/S0714980819000588

Tonkin, R., Freeman, S., Martin, J., Ward, V., & Skinner, K. (2018). First Nations Elders' perspectives of engagement in community programs in Nak'azdli Whut'en, British Columbia, Canada. *Canadian Journal of Public Health*. https://doi.org/10.17269/s41997-018-0125-7

Chapter 13
Case Study 2: Engaging Youth in a Needs Assessment for Programming and Evaluation

Kelly Skinner, Kristin Burnett, Erin Pratley, Barbara Parker, and Brenda Dovick

The Challenge

Our team was hired as evaluators for a larger project intended to offer programming for at-risk youth in a small community in northern Ontario, Canada. The community serves as a hub for many northern and remote First Nations communities and approximately 65% of the student and youth population are Indigenous. When programs for youth are created they often fail to consider the voices of youth in their design. We realized that both in the design of the programming and the evaluation we needed to incorporate youth input at all steps. Thus, we had to figure out a good way to engage in conversations with the youth as well as collect data about their interests and needs. Youth can be a challenging population to engage with and gather input from.

From the larger advisory committee (called the Advisory Circle), we created a subcommittee consisting of the evaluation team and the project coordinator, and we also invited youth workers from the Friendship Centre to collaborate on how to best engage with youth in the community and learn about their interests regarding

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health-related activities and programming. We had started building relationships with organizations in the community, including the Friendship Centre, prior to this project (Parker, Burnett, Hay, & Skinner, 2018). The subcommittee decided to hold a pizza party at the Friendship Centre, and youth were invited to attend and talk about what programming they wanted to see in their community. The subcommittee met several times to plan the event discussing the agenda, advertising, incentives for attendance, the methods of data collection, the design of data collection tools, and the logistics and responsibilities of running the event. We anticipated the biggest challenge would be getting youth to actually attend. We timed the event to start shortly after school from 4 p.m. to 7 p.m. and used the following incentives: pizza, $10 gift cards to Tim Hortons for each attendee, six small door prizes, and one large door prize. Students completed consent forms and were given an extra ticket for the door prize draw once they finished their survey. We also arranged for a shuttle bus to bring students from the schools, including a bus from the nearby First Nations school. We opened and closed the event with drumming and a prayer from an Elder involved with the Friendship Centre. Several youth workers from the Friendship Centre attended the event to facilitate engagement with the youth and to answer any questions the youth had about the survey. The survey was brief and simple with four demographic questions and seven programming questions (see Fig. 13.1).

Fifty youth representing all of the high schools in the community attended and completed the surveys. They also participated in a "dot-mocracy" exercise where

5) What are the 5 activities/programs you enjoy doing the most?
1.
2.
3.
4.
5.

6) What are the 5 activities/programs that you want to be in involved in?
1.
2.
3.
4.
5.

7) Are there activities you want to see adults involved in (which ones)?

8) Are there activities that you want to see Elders involved in (which ones)?

9) Do you use the youth drop in centre in your community? Yes ___ No ____
If no, why?

10) Is there anything that you would like to see at your school (i.e., space/activities) that would make you feel more comfortable and/or happy and/or safe?

11) What do you want adults to know about you?

Fig. 13.1 Brief survey to gather input on youth programming and activities they identified their top programming choices with sticky notes on the wall. Each attendee was then given five colored dot stickers to indicate which programs and activities most interested them. They could choose to allocate all their stickers to the same program/activity or divide their votes among several programs/activities. We analyzed and summarized this data for the project coordinator, project assistant, and the larger project's Advisory Circle so that they could use this information, as direct input from youth in the community, to inform the development of youth programming.

Outcomes and Impact

We thought that perhaps 30 youth would attend the event and were pleasantly surprised to have 50 youth participate. The youth also offered many suggestions about the kinds of programming and activities they would like to see in the community, including interest in both formal programming (e.g., sports, culture, art) and youth type activities (e.g., a space to hang out with friends, video games, listening to music, and going for walks). The youth also were keen to learn specific skills related to culture and community (e.g., beading, drumming, crafts, canoeing, hunting, and fishing) and to engage with and learn from Elders. We were also able to learn why some students chose not to use the youth drop in centre in the community (e.g., less than ideal hours of operation). The input from youth has been incorporated into some of the program planning for the project.

Key Messages

- Carefully consider your target population and the best ways to encourage participation, including addressing any barriers to attending (e.g., transportation, location, time), and incorporating cultural aspects.
- Involve local organizations (e.g., Friendship Centres) and service providers (e.g., youth workers) that have a connection with your target population.

Project Details and Team The larger project is funded through the Local Poverty Reduction Fund of the Ontario Trillium Foundation, an agency of the Government of Ontario (Ontario Trillium Foundation, n.d.), and comprises multiple collaborating organizations in the community including youth service provider organizations, elementary and high schools from both the public and Catholic school boards, the Friendship Centre, and nonprofit organizations. The project is led by an Advisory Circle that meets monthly and acts as a steering committee that includes members from the collaborating organizations. A project coordinator was hired to run the project along with youth outreach workers. A third-party evaluation team provides program evaluation support including evaluation planning, data collection, analyses, and generating evaluation reports for the funder.

References

Ontario Trillium Foundation. (n.d.). *The local poverty reduction fund*. https://otf.ca/what-we-fund/other-programs/local-poverty-reduction-fund.

Parker, B., Burnett, K., Hay, T., & Skinner, K. (2018). The community food environment and food insecurity in Sioux Lookout, Ontario: Understanding the relationships between food, health, and place. *Journal of Hunger and Environmental Nutrition*, 1–18. https://doi.org/10.1080/19320248.2018.1537867

Chapter 14
Learning Activity: Learning How to Include *Hard-to-Reach*, *Hidden*, and *Seldom-Heard* Populations in Research

Shannon Freeman and Martha MacLeod

The Challenge

Undertaking research with persons from populations who are *hard-to-reach* (i.e., persons who are hard to find), *hidden* (i.e., persons who do not wish to be found), and/or *seldom-heard* (i.e., persons who are not often included in study recruitment) often cannot be done in a conventional manner. Engaging these populations (described in Chaps. 11, 14 and 15) challenges researchers to think outside the box, foresee potential challenges, and create in advance a research design that remains flexible to meet the needs of the populations of focus. Creative and innovative approaches to participant recruitment, retention, and data gathering must be developed or employed.

Researchers may be challenged to design a research study that is inclusive of members of these populations as well as to collect data in an accurate and informative way that supports participant recruitment and retention. The study design must be flexible to adapt to needs and changes specific to a target population while retaining methodological rigor.

Overview of the Activity

The aim of this activity is for participants to learn to identify and address unexpected challenges when trying to recruit, design a sampling strategy, and develop a research plan involving *hard-to-reach*, *hidden*, and/or *seldom-heard* populations. This activity provides participants with the opportunity for creative

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problem-solving in teams. Following this is a debriefing period led by an activity facilitator. To ensure participants are immersed in the activity and learn through experience, it is important that the explanation of the purpose of the activity occurs following the activity during the debriefing period. This includes no sharing or discussion of learning outcomes until the activity is completed.

In small groups, participants are given a scenario description and then are asked to design a protocol to identify the population is that they wish to recruit, to then describe the sampling approach, and then to describe their plan for participant recruitment as well as to retain participants for further research opportunities. A variety of challenge cards and resources cards specific to the scenario are provided to the participants. These may be removed at any time during the activity. The purpose of the presence or absence of these cards is to challenge the small groups to adjust or readjust their plans, or to shift gears during the process. Participants are made to rethink their design as they progress. This requires the participants to recognize the importance for a researcher to: foresee potential challenges specific to their population of focus; identify a plan for mitigation strategies; and create a flexible, well-designed, and robust protocol during the design step of research.

Doing the Activity

The goal of the activity for participants is to design a study protocol that identifies the *hard-to-reach*, *hidden*, and/or a *seldom-heard* population they wish to recruit, as well as a sampling strategy, a plan for participant recruitment, and a plan for retention of participants for further research opportunities.

Do not distribute any learning outcomes ahead of the activity. The facilitator may provide a list of learning outcomes to participants along with tips to consider following the debriefing to this activity. This activity may take 45 min to 1 h.

Participants are seated in small groups of approximately 6–8 people. Each group will be given an individual scenario of a study they are expected to conduct. They also receive a resource card and a challenge card specific to their scenario (see examples provided). During the activity, session facilitator(s) circulate among each group and provide guidance on what directions show promise and what aspects require additional thought. At the midpoint of the activity (approximately 20 min in), the session facilitator comes to the group, assesses the groups' progress, and may remove one, both, or neither of the challenge or resource cards. If the group has addressed existing issues on the card, the facilitator should take away the original card and replace it with an alternate card. The facilitator may choose to switch out both the original challenge and resource cards at the same time and provide a challenge alternate and a resource alternate card or the facilitator may choose to switch just one of the cards. Groups should not be told ahead of time that this switch will occur. It is not required that all cards be switched by the facilitator in the same way for all groups involved. As the groups must readjust their plans accordingly to address the replaced cards, this process may be intentionally disruptive to the groups' planning process.

Alternate cards should provide a different aspect that needs to be addressed. A facilitator may choose not to provide an alternate card at their discretion if the facilitator observes that a group is still productively working through the issue raised by the original resource and/or challenge card.

In the last 10 min of the activity, each small group of participants are asked to reflect on what they have learned and to identify one key learning from the exercise. Each small group then selects one member to present their identified key learning in a 2 min timed presentation to the whole group during the debrief period.

Debriefing: Following the activity, one representative from each small group will present to other participants a key learning identified by their group from their scenario.

1. Each group will select one representative to present orally (no flip chart or PowerPoint slides) on one thing that they have learned from the exercise. (Groups are not expected to present everything, they just have to share one major learning that will stay with them.) To keep it moving, the session leader may set a 2–3 min time limit per group to present their learnings. With 5-6 small groups of participants at 2 minutes per group the presentations could take approximately 15–20 min.
2. The lead session facilitator then presents a summary of what the groups have identified as key learnings and can add on a 10 min PowerPoint presentation highlighting practical tips and suggesting further resources for session participants. During this debrief, the facilitator may discuss the learning objectives for this activity.

Session Preparation

- Photocopying of the scenarios, cards, and debrief handout describing learning outcomes and list of key considerations specific to the research area (example attached under learning outcomes). It is anticipated that the facilitator creates a debrief handout that is specific to the research focus areas of the participants.
- For each small group, the facilitator should develop a unique scenario with relevant challenge, challenge alternative, resource, and resource alternative cards. It is recommended that each group be given a different scenario with relevant cards.
- Optional PowerPoint and computer for the Lead Session Facilitators' presentations at the end of the debriefing.
- Participants are to be seated in roundtables for group work in a room/area where it is okay for them to be noisy.

Learning Outcomes (Note: Please Do Not Distribute to Activity Participants)

After participating in this activity, the participant can expect to:

- Understand the difference between hard-to-reach, hidden, and seldom-heard populations.
- Create a workable protocol that sets the foundation for sustained research relationships with hard-to-reach, hidden, and/or seldom-heard populations in research.
- Develop an appreciation for challenges faced when conducting research with these populations.

Learning Outcomes List to Be Handed Out During Debrief

Following this activity, participants should consider how they will:

- Identify hard-to-reach, hidden, and/or seldom-heard populations.
  - Carefully consider *who* is your target audience.
- Address challenges to recruitment.
  - Consider—where can I find those whom I wish to meet?
  - Identify strategies to make initial contact.
  - Identify potential/existing barriers to recruitment (e.g., mistrust of strangers, history of mistrust of researchers, lack of health literacy, participant fear of loss of anonymity).
- Address challenges to retention.
  - Recognize how you can invest in relationship building.
  - Consider how to make relationships sustainable.
  - Identify which routine and nonroutine strategies may work.
- Address challenges to sampling.
  - Consider feasibility and trade-offs of employing a probability vs. non-probability sampling options.
- Develop meaningful and authentic relationships with participants.
  - Become aware of one's own attitudes, experiences, and perspectives as well as how these may affect one's ability to engage with population of focus.
  - Develop cultural awareness skills.
  - Be mindful of existing and/or perceived power imbalances.

Learning More

- Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., … Hughes, C. (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology, 14*(1), 42.
- Canadian Institutes for Health Research. (2017). CIHR strategy for patient-oriented research. http://www.cihr-irsc.gc.ca/e/41204.html.
- First Nations Information Governance Centre (FNIGC). (2018). The First Nations Principles of OCAP®. http://fnigc.ca/ocap.html.
- Zweben, A., Fucito, L. M., & O'Malley, S. S. (2009). Effective strategies for maintaining research participation in clinical trials. *Drug Information Journal, 43*(4), 459–467.

Activity Resource Examples

Example of Scenarios

Scenario #A—Dog Ownership and Homelessness

Situation: A newly developed board of directors of a homeless shelter in a large urban center recently passed a policy banning homeless men from bringing their dogs within 10 m of their shelter. You have been approached by two homeless older men who are desperate to keep their dogs with them at all times and who are afraid of what would happen if they were to leave their dogs alone unsupervised. Both older men are struggling with addictions and unknown mental illnesses. As a result of the new policy, they have been sleeping outside and have been unable to access services from the homeless shelter. Winter is coming.

Proposed research questions: How large of an issue is this? How prevalent is dog ownership among older homeless men? Is this issue limited to urban centers or pervasive across all geographies? What are the social benefits of dog ownership among homeless older men? How will this new policy affect the health, safety, and well-being of homeless older men who own dogs?

As a research team, you need to: identify what role can research take to help address this problem in a timely manner? Please identify who your audience will be for this research.

RESOURCE CARD: You have been given the opportunity to speak directly with the homeless shelter's director and the board chair. The shelter director seems to be on the side of the homeless men, however, the director has yet to speak up in discussions with the board chair	**FLIP SIDE:** You approach the homeless shelter and no one will talk to you
CHALLENGE CARD: There are no obvious sources of funding to help you conduct a research study	**FLIP SIDE:** The mayor has announced a call for research to address homeless issues in the city

Scenario #B: Motivations for First Time Geriatric Offenders

Situation: A news story was run recently describing a population of older adults who newly committed crimes purposefully to be imprisoned. The news story described the experiences of two older men aged 65 and 68, living in extreme poverty who could not afford to pay their rent, needed medications that were not covered by the low income pharmaceutical support program, and who were at risk of homelessness. Unable to access any community supports these two men, who were lifelong friends, resorted to criminal activity so they could receive meals and a place to sleep in prison. The prison is a major employer for a medium-sized city located in the middle of a predominantly rural and remote area. The mayor of the city (population 70,000) is keen to examine this issue further and better understand whether this was a sensational news story or if there is some truth behind the motivations among geriatric first time offenders.

Proposed Research Question: Why do older adults purposefully commit crimes in later life? What proportion of persons who commit crimes in later life do so due to challenges associated with aging? What community supports may be developed to address this issue.

As a research team, you need to: identify how prevalent this is and to describe in-depth what are the motivations for first time criminals over the age of 65.

RESOURCE CARD: You have previous experience conducting a research study on older adults who were released from a major prison in the United States	**FLIP SIDE:** There are wildfires across the province and all prisoners were relocated to surrounding corrections facilities. No one returns your telephone calls or e-mails
CHALLENGE CARD: You have no connections in corrections in your country	**FLIP SIDE:** Your neighbor is a prison guard and has offered to help introduce you to a few people

Chapter 15
Building Relationships with *Hard-to-Reach*, *Hidden*, and *Seldom-Heard* Populations in Research

Shannon Freeman, Kelly Skinner, Laura Middleton, Beibei Xiong, and Mei Lan Fang

The Challenge

Authentic engagement of people as research participants in a meaningful, collaborative, and mutually beneficial way involves investment in the development of a relationship between the researcher and the person who is participating in the research process. The development of an authentic research partnership is rooted in three components. First is the *development of a relationship of mutual respect* by both the researcher and the research participant for each other. Through sharing, listening, dialogue, and active communication, both the researcher and the research participant may value the experiences of the other to form understanding of their similarities and uniqueness. Second is the *development of a collaborative relationship* "rooted in trust, reciprocity, and diversity, where shared learning is valued"

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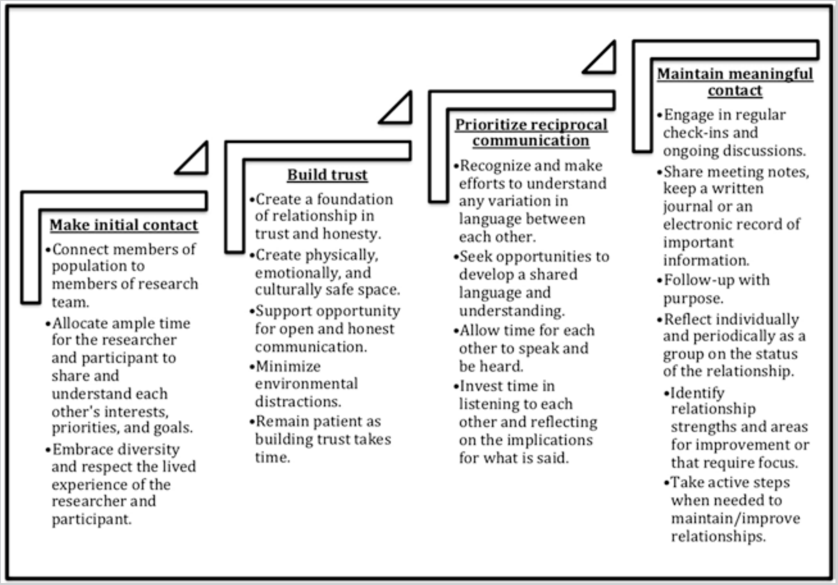
Box 15.1 Steps to Building Authentic Partnerships



Note. Based on the Authentic Partnership Model described by MAREP (2019). Accessed at: https://uwaterloo.ca/murray-alzheimer-research-and-education-program/about/authentic-partnership-model.

(Murray Alzheimer Research and Education Program (MAREP), 2019). Throughout the relationship, both the researcher and the research participant should have opportunities to learn, grow, and receive positive benefits. Third is *viewing the relationship as more than for the sole purpose of participating in a single research project*. Steps to establish this are further detailed in Box 15.1.

An authentic research partnership prioritizes the research process and engaged relationship as much as it does the individual research project. Therefore, time should be invested in all steps of the relationship from the initial contact, through the research process, and into the future. Participants may be engaged early in the research process, working with researchers to identify research priorities and questions and generate research hypotheses. As the relationship continues, attention should be given to remain in regular contact, not only for formal research team planning meetings or for participation in research study activities but also to remain connected and keep up-to-date on what is happening. This contact could be a discussion over coffee at a local coffee shop or sharing of interesting and relevant materials through email.

Key Ideas

Key areas of focus in this chapter are:

- Developing meaningful and authentic relationships.
- Respecting and being aware of power dynamics and of the historical treatment and past experiences.
- Maintaining and sustaining relationships throughout the research process and over time.

Developing Meaningful and Authentic Relationships

One of the most important and most time-consuming aspects of building a relationship between researcher and research participants and partners is to develop trust. While this can be very challenging and resource intensive, investing in the relationship by spending time to build trust before or at the beginning of the project can be very beneficial. This may establish a foundation upon which to build more than just a relationship for a project and instead a lasting and sustainable partnership extending across time.

Employing a participatory action research design or an integrated knowledge translation lens supports development of research that can better align with the goals of the community. Researchers should consider connecting as early as possible in the research process and involving participants in setting the directions and goals of the research. This may involve community consultation with gatekeepers and leaders at foundational steps to determine research direction and goals well before participants would normally be engaged. Researchers should carefully budget for ample time to allow for community consultation to proceed at a pace dictated by participants and not driven by tight timelines, such as a grant application or reporting deadline. A substantial amount of additional expenses should be considered to support transportation and meeting expenses, especially when dealing with geographically dispersed populations.

It is important to discuss research processes early on in the relationship. These could include ownership, control, and access to the data; level of involvement expected of community members or stakeholders in data collection, analyses, interpretation of findings, and reporting; as well as the strategy for dissemination or knowledge translation plans at the end of the research. For example, specific communities, organizations, or populations may not want to be directly identified in academic outputs or may only want to use the research for internal quality improvement or evaluation purposes. Other partners may wish for equal recognition as co-investigators on grants or co-authorship on written reports and manuscripts.

In building relationships, researchers need to be aware about one's own attitudes, experiences, and perspectives and how this may affect the researchers' ability to engage with the population of focus. Researchers should reflect on their mannerisms, behaviors, etiquette, biases, and other nuances to understand how these characteristics may be viewed by research partners and participants and influence meaningful engagement. Researchers need to consider tailoring of language to communicate with others in a respectful manner that recognizes and acknowledges the value of the participants' voice(s). Especially when engaging in emotionally challenging research topics such as historical trauma, neglect and abuse, or negative life events, researchers should set aside time for self-reflection and self-care. Conducting research in teams can provide opportunity for peer support and the sharing of experiences during research without risking the threat of confidentiality of participants. Researchers should consider developing a self-care plan prior to beginning research activities.

Respect and Awareness of Power Dynamics and of the Historical Treatment and Past Experiences

Researchers should keep in mind that there may be an inherent power imbalance (see also Chap. 11) when a researcher engages with participants, especially if the population is vulnerable. The first step to addressing an imbalance is for the researcher to acknowledge their own preconceptions and biases related to the research and target population. Secondly, it is important to reflect on and acknowledge the value of diverse experience, knowledge, values, and practices that members of the target population bring to the research. Engaging members of the target population as true collaborators and co-researchers within a participatory research model can reduce inequity in the relationship. One opportunity early in the research to use this participatory approach could be to co-design research questions that truly address community needs and not just the needs perceived by the researchers. This has the added benefit of creating research questions and studies that equally benefit the target population and the researchers. Specific practices within participatory research can further reduce power imbalances. Examples of these include co-developing terms for the research team, rotating the person chairing research meetings or using independent facilitators, and alternating the location of meetings between research and community sites.

When working with First Nations communities, it is important to understand the First Nations principles of "OCAP®." The four components of OCAP® are ownership, control, access, and possession. For researchers, there is a Fundamentals of OCAP® online course offered by the First Nations Information Governance Centre (FNIGC) and Algonquin College. OCAP® is a registered trademark of the FNIGC (www.FNIGC.ca/OCAP). "OCAP® respects that rights of First Nations communities to own, control, access, and possess information about their peoples are fundamentally tied to self-determination and to the preservation and development of their culture" (FNIGC, 2019). *Ownership* refers to how a community or group owns their information collectively; *control* refers to the First Nations control over the research at all steps of the project; and *access* refers to the First Nations having access to the information and data (FNIGC, 2019). This may include formal protocols, such as a code of research ethics determined between the researchers and First Nations group; and *possession* refers to the physical control of data as a mechanism where "ownership can be asserted and protected" (FNIGC, 2019). To conduct research respecting OCAP® principles, researchers should budget extra time and funding resources (e.g., for travel) as this will likely require extensive community consultation at the beginning of the research and throughout the project.

Box 15.2 Challenges When Doing Research with First Nations Communities

Building respectful relationships with First Nations communities and organizations takes a lot of time, often over the course of several years. Maintaining these relationships also requires time and effort, including face-to-face engagement and opportunities for discussion and communication regarding all phases of the research. For example, Castleden and colleagues (2012) conducted an exploratory qualitative case study of interviews with community-based participatory researchers that work with Indigenous communities and titled the paper, "I spent the first year drinking tea…." This quote came from one of the participants in this study when she described a conversation with her Dean: "My Dean asked me two years into my project why I hadn't published yet out of it and he had no idea what I was talking about when I told him that I spent the first year drinking tea, you know?" (Castleden, Sloan Morgan, & Lamb, 2012, p. 168). Spending the time in Indigenous communities necessary to build respectful relationships of mutual trust was cited as one of the greatest challenges for the researchers interviewed. In this study, the length of time of the partnerships between the researchers interviewed with Indigenous communities or organizations ranged from 2 to 30 years (Castleden, Sloan Morgan, & Lamb, 2012).

Increasing shifts in immigration patterns bring together diverse populations and introduce new cultures that encompass new languages, ethnicities, and religions (Kirmayer, 2012). Cultural awareness is an important skill for researchers to acquire, particularly when the research being undertaken requires working with persons of diverse cultural backgrounds. However, there has been growing concern and heightened recognition by the health community that the western model of delivering health-care services may not result in optimal care and health outcomes for ethnic minority groups (Fung, Lo, Srivastava, & Andermann, 2012). To better accommodate recent and settled ethno-cultural groups, health-care providers and health researchers must consider the challenges experienced by ethno-cultural populations when experiencing health and/or accessing health and social care. For example, in pediatric mental health care, Godoy and Carter (2013) emphasize structural issues associated with cognitive appraisal processes that can contribute to heightened rates of unmet need among ethnic minority children. Cultural awareness is not just about ethnic background, but it can be about the culture of living with a particular health challenge. For example, cultural awareness is also important in building organizational capacity to provide better training and support to providers and researchers that serve or work with people living with substance use disorder and/or individuals living with HIV/AIDS (Gregory et al., 2012). As such, there is no cookbook for how to be culturally aware; however, adopting a standpoint theoretical perspective can help facilitate joint problem-solving (Smith, 2005).

Fostering Relationships Throughout Research Process and Over Time

Researchers must not forget that an authentic research partnership not only requires time to be invested to begin and create a relationship but that it also requires time to be invested in an ongoing manner to sustain connection over time and foster continued meaningful engagement. This requires the researcher and partners to transition from a focus on individual outcomes to a consideration of the outcomes for each other not only for the immediate time but also for the future. The researcher and research partner should reflect on the balance of outputs, learnings, and outcomes of the relationship with the time and resources each partner has invested into the relationship. When either party fails to recognize the value received in comparison to the level of contributions and costs incurred, then there can be ambiguity and feelings of inequity. This can negatively affect the relationship and become a substantial threat to sustainability if one or both partners perceive an unequal or unfair balance. Researchers need to consistently check in and recognize the value each partner contributes. To do this a researcher should remain humble and appreciative remembering that not only are they busy but so too are their partners.

It is important to remember the phrase "Nothing about us without us" when not only designing and undertaking a research project but also following project completion and sharing of research findings. Partners can be included in knowledge dissemination activities in ways such as co-presenting findings at community forums or academic conferences as well as being invited to co-author written articles. Team members can be engaged to support the sharing of project successes with others not only in academic journals of interest to the researcher but also in nonacademic formats such as reports, magazine articles, interviews on community radio, small posters put up at community centers, or social media posts (see Box 15.3). Researchers may also consider sending electronic or paper copies of newly published papers to community partners especially if the articles are not published in an open access format (Table 15.1).

Box 15.3 Leverage Social Media to Keep Engaged with Community Partners

Researchers who are active on social media personally may also consider using social media professionally to leverage their existing partnerships. Diversifying the types of platforms used can include expanding from one platform to utilizing multiple platforms, including social networking, microblogging, and video sharing. Social networking sites such as Facebook and LinkedIn can be great to share project outcomes and perspectives with broader audiences as well as provide a way to connect and communicate with community partners. Researchers may consider separating personal from professional social media accounts to increase the control over shared information in a global context. Sharing articles on social networking sites allows researchers to target others with shared interests and can spark partnerships to expand and to inspire ideas for future research collaborations. Once connected, researchers and their partners can tag each other in posts or share stories of common interest. Microblogging sites such as Twitter or Tumblr can enable the project team to create a narrative using more concise language. Consider creating a project hashtag that links to all team members. Video sharing on sites such as YouTube, Vimeo, or Facebook Live can bring life to narratives. Viral videos can be very powerful to spread messages and stories to a large audience in a relatively short time span. This can increase awareness of shared projects, engage audiences in a visual manner, and put a human face to an issue of importance. The researcher and partners must consider the amount of resources available to support social media as well as platforms where all involved feel comfortable to share findings and remain connected. Successful development and maintenance of a social media strategy can be considered a research output and involves planned utilization of resources (i.e., time, money, and available manpower). These aspects should be considered early on in the research process, and resources should be part of the project budget.

Key Messages

- Prior to engaging participants, researchers should be aware of their own attitudes, experiences, and perspectives and reflect on biases they might hold.
- Development of a trusting, respectful, and meaningful relationship between researchers and participants requires investment of time and effort prior to the start of research and respect and value given for different experiences and perspectives.
- An authentic research partnership involves engaging members of the target population as collaborators or co-researchers through a participatory research mode. Collaborators and co-researchers from the target population may work with researchers to co-design research questions, research design, and analysis and interpretation of results.

Table 15.1 Product Innovation Pathway (PIP) model—building authentic relationships with hard to find, hidden, and seldom heard populations

PIP level	PIP description	Key activities
1	Concept	• Develop meaningful and authentic relationships[a] • Allocate and spend considerable time before or very early in the project to build relationships • Identify and consider your own biases and assumptions[b]
2	Planning	• Be aware of, respect, and understand power dynamics, historical treatment, and past experiences • Reflect on your own biases and assumptions[b] • Take steps to lessen power imbalances by rotating facilitation of meetings, hiring an independent facilitator, and/or alternating meetings sites
3	Development	• Allocate ample time to maintain relationships • Establish a foundation of trust and honesty between researchers and the target population • Establish regular contact with community partners and participants[a] • Consider developing social media platforms to communicate outputs of the research and to communicate with each other • Continue to reflect on your own biases and assumptions[b]
4	Testing in a real-world environment	• Keep in regular contact with community partners and participants[a] • Continue to reflect on your own biases and assumptions[b]
5	Outcomes and impact	• Develop and maintain social media platforms to communicate outputs of the research and to maintain contact • Establish a sustainable strategy to maintain contact with community partners and participants[a] • Continue to reflect on your own biases and assumptions[b]

Note. [a]It is important to keep regular contact with community partners and participants at all steps. [b]Researchers should continually reflect on their own biases and assumptions and consider how that may affect the relationship with community partners and participants at each step of the research process

- Authentic research partnerships can reduce the power imbalance between researchers and participants and are more likely to result in research that is mutually beneficial to the target population and to researchers.
- Time and effort are also needed to maintain authentic relationships over time. This can be done through regular communication, involvement in research dissemination activities, and connecting outside of research through social gatherings or even social media.

Learning More

- Canadian Institutes for Health Research. (2017). CIHR strategy for patient-oriented research. http://www.cihr-irsc.gc.ca/e/41204.html. This website describes how researchers can use patient-oriented research to engage patients, caregivers, and members of the community with lived experiences as partners in the research process.

- Canadian Institutes for Health Research. (2017). Patient engagement. http://www.cihr-irsc.gc.ca/e/45851.html. Patient Engagement. This webpage describes with greater detail patient engagement in research.

MAREP. (2019). Authentic Partnership Model. https://uwaterloo.ca/murray-alzheimer-research-and-education-program/about/authentic-partnership-model. This resource provides further details on the guiding principles and enablers to developing an authentic research partnership.

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References

Castleden, H., Sloan Morgan, V., & Lamb, C. (2012). "I spent the first year drinking tea": Exploring Canadian university researchers' perspectives on the ethical and institutional tensions of community-based participatory research involving indigenous peoples. *The Canadian Geographer, 56*(2), 160–179.

First Nations Information Governance Centre (FNIGC). (2019). The First Nations Principles of OCAP®. http://fnigc.ca/ocap.html.

Fung, K., Lo, H. T., Srivastava, R., & Andermann, L. (2012). Organizational cultural competence consultation to a mental health institution. *Transcultural Psychiatry, 49*(2), 165–184.

Godoy, L., & Carter, A. S. (2013). Identifying and addressing mental health risks and problems in primary care pediatric settings: A model to promote developmental and cultural competence. *American Journal of Orthopsychiatry, 83*(1), 73–88.

Gregory, H., Van Orden, O., Jordan, L., Portnoy, G. A., Welsh, E., Betkowski, J., … DiClemente, C. C. (2012). New directions in capacity building: Incorporating cultural competence into the interactive systems framework. *American Journal of Community Psychology, 50*(3–4), 321–333.

Kirmayer, L. J. (2012). Cultural competence and evidence-based practice in mental health: Epistemic communities and the politics of pluralism. *Social Science & Medicine, 75*(2), 249–256.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. New York: Rowman & Littlefield.

Chapter 16
Case Study: Creating Integrated Working Relationships with Frail Older People—The Smart Distress Monitor Project

Judith Sixsmith

The Challenge

When engaging in cross-disciplinary and cross-sectoral research and development projects, it is vital to reveal the expertise within the team to establish that all necessary knowledge is available. In addition, the roles and responsibilities of each partner or organization need to be jointly agreed upon so that team members know who to approach when they require support and who is the best person to tackle particular challenges. It is also important to ensure continuous feedback on each partner's input so that any difficulties arising are made visible and shared solutions are put in place. Finally, deciding together on how to resolve any conflicts is a critical part of a project terms of reference. If attention is not paid to expertise, roles, responsibilities, feedback, communication, and conflict resolution, then the project is at risk of breaking down and the chance of integrated knowledge generation will be compromised.

This case study focuses on an aging and technology project (Pratesi, Sixsmith, & Woolrych, 2012) to develop a prototype smart distress monitor that could passively monitor the (in)activity of older adults in their everyday home environment for 24 h a day. The idea was that the monitor would build up a picture of the normal pattern of a person's daily activities and then identify abnormal or unusual patterns of (in) activity (e.g., if a person fails to get out of bed for a whole day when they are usually up and about before 8 p.m. or spending inordinate amounts of time in the bathroom). Deviations from their normal behavioral patterns could suggest the need for support and an alert could be delivered to a neighbor, family member, friend, first responders, or social care key workers. The main benefit of such a system lies in

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passive smart detection, such that the person would not need to wear an alarm, reach an alarm if they have fallen or activate an alarm themselves.

To avoid creating an overly invasive "big brother is watching you scenario," older adults themselves were required to guide the development of the project so that they could identify, together with the academics and developers, plausible and acceptable solutions.

At the outset of the project, an advisory and decision-making group of eight older adults was created. This case study describes the key challenges facing the integration of three knowledge bases (the experiential knowledge of the older adults, the academic knowledge of the university team, and the technological knowledge of the developers) and how such difficulties were overcome. In particular, the success of the project depended on prioritizing the experiential expertise and the integration of older adults as advisors and decision-makers in the project through genuine participatory processes (see Pratesi, Sixsmith, & Woolrych, 2013). These issues are discussed in these sections: (1) coming to terms with different expertise; (2) dynamic roles, responsibilities, and feedback; and (3) conflicts and friendships.

Coming to Terms with Different Expertise

Initially, the development team approached the academic team to begin the project. Both developers and academics agreed that older adults were necessary to produce a relevant and useful smart distress monitor. At this point, the academic team called on their research contacts, family, and friends to locate interested volunteers. Most of the older adults that were approached shied away from the project, feeling that it was a strongly technological project and that they were not technologists. The academics put on several events to talk about older adults, health, and the challenges of living alone in poor health. By framing the research within the context of everyday life, older volunteers began to see the relevance of their everyday life expertise and how it intersected with their knowledge of the problem area. Interactive sessions were then held to discuss new technological options for the monitor. What began as technological and academic talks soon transformed into a series of dialogues in which the older adults contributed their ideas on what would and would not be acceptable in their lives and in their homes, creating a new set of solutions for the monitor. Each of the stakeholder groups had begun the process of recognizing their different but congruent expertise, all of which was required to make a success of the project.

Dynamic Roles, Responsibilities, and Feedback

Given the diversity of stakeholders involved in the project, it quickly became clear that while the academic and developer roles were established during the proposal writing stage, the older adults' roles and responsibilities were less obvious. The academics set up regular meetings between themselves and the older adults' group to discuss project progress and to identify when and where their input was possible and advisable and to feed back this information at project meetings with the developers. This, however, created a situation where the academics were seen to be leading the older adults' enterprise while the developers led the technological development. The academics were occupying the position of intermediary. Unsurprisingly, the older adults began to feel as if they were less integral to the project. A terms of reference document was then drawn up in a meeting between academics, older adults, and developers outlining that monthly feedback would flow across all partner groups, in accessible language and presented electronically as well as in hard copy. This way, roles and responsibilities were formally acknowledged, and feedback became central to the project. The terms of reference were revisited at the request of any partner, creating an environment of trust and ownership across the three partner groups and ensuring that a mechanism of change was activated as part of the working relationships.

Conflicts and Friendships

Inevitably conflict arose during the project. Members of the older adults' group did not always agree or enjoy working together, the developers sometimes felt distanced from the other partners, and the academics felt that their expertise was not always valued. The terms of reference document stipulated that any conflicts could be aired within joint meetings. However, this was initially difficult to do as project business predominated over social issues which were sidelined, and formal conflict resolution mechanisms enshrined in the terms of reference remained unused. As the first Christmas approached, the partners decided that a Christmas celebration would be nice and could conclude the upcoming business meeting. The older adults suggested the business meeting and subsequent celebration could take place in a local pub. All agreed, and during that business and social event, friendship relationships emerged. In the New Year, photographs of the event were shared alongside humorous stories. Gradually, the importance of nurturing social relationships percolated the project bringing with them familiarity, reciprocity, and the sense that difficulties/conflicts could be brought up and discussed in an open and trusting atmosphere, much as suggested by Jackson, Sixsmith, Mihailidis, and Sixsmith (2015) in their work on the building of transdisciplinarity in research work.

Outcomes and Impact

The project was seen by the funding research council as an example of excellent practice in terms of knowledge integration and the involvement of older adults in research and development. The final developed prototype reflected many, but not all, of the requirements and concerns of the older adults. Indeed, in-home trials of the prototype proved so successful that trial participants felt safer and more secure in their homes with the smart monitor and wanted to keep the device on conclusion of the trials, asking that they be informed if the device was available to purchase.

Key Messages

- Establishing the different expertise bases, how they fit together and how they are valued across the partnership is essential to produce a more holistic, integrated approach to research and development.
- Articulating the roles, responsibilities, and feedback mechanisms requires careful thought and continued attention as the dynamics of the project change. The creation of an adaptable terms of reference document helps to formalize this as a shared process across the project.
- As projects progress, working, personal, and social relationships are formed. These relationships are very important to the smooth running of the project, strengthen willingness to meet project objectives and deadlines, and increase the enjoyment of all involved.

Project Details and Team The Smart Distress Monitor project was funded by the Technology Strategy Board of the United Kingdom (2008–2011). Project funding was dependent on an industrial lead and an academic partner working in joint partnership. The importance of input from other stakeholder sectors was recognized in the call for funding, particularly the integral involvement of older adults which, in this project, was accommodated in an advisory group comprising managers, nurses, and retirees from small- to medium-sized enterprises.

References

Jackson, P., Sixsmith, J. Mihailidis, A., & Sixsmith, A. (2015). Perspectives on collaboration in technology innovation for ageing. In *International conference on smart homes and health telematics conference* (ICOST), Geneva, Switzerland, 10–12 June (pp. 27–37).

Pratesi, A., Sixsmith, J., & Woolrych, R. (2012). Participatory design for future care related technologies: Lessons for the Smart Distress Monitor Project. In I. Serrano-García (Ed.), *Psicología Comunitaria Internacional: Aproximaciones a los Problemas Sociales Contemporáneos* (Vol. 2, pp. 183–196). Puebla: Universidad Iberoamericana Puebla (Mexico).

Pratesi, A., Sixsmith, J., & Woolrych, R. (2013). Genuine partnership and equitable research: Working "with" older people for the development of a smart activity monitoring system. *Innovation Journal: The Public Sector Innovation Journal, 18*(3), 1–17.

Chapter 17
Addressing Real-World Problems Through Transdisciplinary Working

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The Challenge

Transdisciplinary working aims to develop solutions that address real-world problems such as the challenge of improving the health and well-being of people. Also known as *wicked problems*, real-world problems are defined as complex, context-oriented social issues that are difficult to resolve through a traditional single-disciplinary approach to research (Rittel & Webber, 1973) (see Chap. 4, An introduction to transdisciplinary working). Solving real-world problems can be challenging because this requires integrating various perspectives and knowledge from different academic disciplines and experiential/professional sectors (Boger et al., 2017).

There are a number of transdisciplinary working strategies that can help translate research findings into real-world impact. This chapter provides a brief overview of four of these strategies focused particularly on translation into real-world impact; however, each strategy is further developed in its own chapter in this book:

- Community involvement in research (see Chap. 6).
- Knowledge mobilization strategies and plans (see Chap. 47).

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- Education, training, and capacity building for future innovation (see Chap. 19).
- Commercialization strategies and plans (see Chap. 42).

Key Ideas

Community Involvement in Research

Prioritizing community involvement is key to the success of research projects that aim to have a real-world impact. Active engagement and collaboration with a variety of professional (e.g., healthcare, commerce) and experiential (e.g., older adults, carers) stakeholders from a community affected by a problem of interest leverages the necessary knowledge into a project (Boger et al., 2017; Sixsmith, 2013). Community involvement can be, therefore, the deciding factor in the success, or failure, of an effective real-world solution.

There are five key steps to establishing successful partnerships between researchers and community members: (1) identify, engage, and select appropriate partners; (2) build rapport and trust; (3) co-create and share clear goals and objectives; (4) develop mutually beneficial outcomes; and (5) establish governance, procedures, rules, and decision-making structures (Diep, Sixsmith, Kirkland, & Panek, 2018). To identify, engage, and select the right partners (e.g., organizations, individuals), researchers need to have clear project goals and values, map these onto potential partner expertise and skills, and also assess potential partners' values, needs, and limitations (Hebb & Thaker, 2014). Effective partnership building with community members also requires negotiation about goals, processes, and the partnership's structure as well as each partner's roles and responsibilities (Diep et al., 2018). This process should be undertaken at the onset of a project and can be formalized via a memorandum of understanding or a contract (Hebb & Thaker, 2014) (see Terms of Reference sample in Diep et al., 2018).

To facilitate real-world impact, project objectives should be jointly developed with the community partners and should be based on their issues and needs (Boger et al., 2017). Also, it is critical for researchers to involve community partners at all project steps as it not only enables researchers to learn about, understand, appreciate, and attend to the community's multiple and intersecting social, environmental, legal, and technical needs, perspectives, and factors (Orozco & Cole, 2008; Pohl & Hadorn, 2008), but it also supports knowledge mobilization and enhances uptake of the research outcomes in real life (Altman, 1995). Box 17.1 describes an example of engaging community stakeholders to better understand their needs.

Box 17.1 The Mental Health Needs Assessment: Engaging Students in the Project

Supporting postsecondary students' mental health is a *wicked* problem because mental health is multifaceted and influenced by many factors. To develop solutions to this problem, the Mental Health Needs Assessment (MHNA) project was launched with the aim of exploring university students' mental health needs and fostering a healthy learning environment. The project team was comprised of university faculty members, university student affairs staff, and student members. Guided by a participatory action research approach, the project team identified and engaged with key community stakeholders from the planning phase of the project: students at the university and the Mental Health Awareness Club (MHAC), a student-led organization established to increase mental health awareness and mitigate stigma toward mental illness on campus. The roles of the key stakeholders included co-designing the MHNA project with the team, assisting the team during all stages of the project (e.g., participant recruitment, data collection and analysis, identification of actions to address students' mental health issues and needs, knowledge mobilization), and actively engaging in the decision-making process throughout the project. Informed by the findings, the MHAC is implementing processes to promote students' mental health in the university community. For more information, see Lee et al.'s (2018) case study.

Knowledge Mobilization Strategies and Plans

To create a positive difference in people's lives, knowledge generated through research must be passed on to key stakeholders—those who would like to use the knowledge—in the right format and in a timely manner so that they can use that information to make decisions that will lead to positive changes in the real world. To effectively distribute research outcomes to a range of key stakeholders (especially nonacademics) in preparation for the real-world application of those outcomes, it is critical to pay attention to and strategically plan knowledge mobilization practices for different stakeholders. The Knowledge Translation Planning Template developed by Barwick (2008, 2013) provides guidance on following essential components of a knowledge translation planning process: identifying research partners who need to be involved in the knowledge mobilization planning process; defining their roles and responsibilities; and identifying target knowledge users and/or recipients. For each knowledge user and/or recipient group, researchers should recognize specific knowledge requirements, develop knowledge mobilization goals, and identify key messages to be delivered and specific strategies to be utilized (e.g., preferred language of communication) (Barwick, 2008, 2013). It is also important for researchers to consider using diverse communication mediums and strategies to reach all stakeholders in a way that best suits their needs and preferences. Box 17.2 offers an example of a multi-method approach to knowledge mobilization.

Box 17.2 Knowledge Mobilization in an Evaluation of the Effects of Interinstitutional Relocation Between Long-Term Care Homes

Following the completion of a 2-year longitudinal project designed to explore how residents, their family members, and care staff experienced the transition from an institutional long-term care (LTC) facility to a purpose-built home-like setting in western Canada, practice implications and guidelines were presented during a Research Day. This event was organized by the research team in collaboration with a nonprofit organization that provides senior housing and care and that funded the project. The aim with the event was to disseminate the project outcomes to research participants, community members, and other key stakeholders. For this event, multiple knowledge mobilization strategies were used: interactive data presentations were offered (e.g., narrated PowerPoint presentation); posters describing evaluation results were displayed in prominent positions in a shared hall at a research site that is accessible to community members; informal researcher-attendee dialogues about the results were conducted; a brochure outlining key messages from each poster was produced; and guidelines for interinstitutional transition to support resident and staff well-being were developed. For more information, see Battersby, Canham, Krahn, and Sixsmith (2017).

Planning and then implementing an evaluation process to assess the success, or otherwise, of knowledge mobilization goals and the impacts of disseminated knowledge is crucial (Barwick, 2008, 2013). Barwick notes that multiple indicators can be used for evaluating whether or not knowledge mobilization goals have been achieved: the number of people using or adapting the disseminated information to inform policy, health practice, and programs; qualitative and quantitative changes in attitude; system changes; and the number of people seeking out and disseminating the information (i.e., distribution numbers, requests for copies of reports, media coverage). Tracking the use and impact of disseminated knowledge is an essential part of assessing whether or not research outcomes have had a real-world impact.

Education, Training, and Capacity Building for Future Innovation

Enhancing the research preparedness and critical thinking skills of students, early career researchers, and other trainees contributes to future knowledge building and translation. Training researchers to understand the principles, benefits, and methods of transdisciplinary research increases capacity for such research to be conducted and ultimately expands the researchers' capacity to develop innovative and transformative solutions to real-world problems. For example, providing early career researchers with experiential professional opportunities to work within commercial, public, voluntary, or community-based organizations can be a very effective way of not only enhancing their capacity and skill to engage with these communities but also supporting communication of knowledge across academic and professional sectors. Box 17.3 explains how this approach was successfully applied in an urban regeneration project.

Box 17.3 Urban Regeneration and the Co-location of Researchers

A northern United Kingdom local authority began a program of urban regeneration with a focus on improving the well-being of local residents. University researchers were contracted to evaluate how well the process and practice of regeneration of the local area had improved resident well-being. One of the researchers worked as a *researcher-in-residence* and was located for 4 days a week in the urban regeneration office and at the university for 1 day a week. Being embedded in the local regeneration office, which in itself was located in the regeneration area, the researcher was able to directly share information between the university and the regeneration professionals. This meant that theoretical and critical ideas about the regeneration informed the regeneration process as it progressed. Similarly, tacit understandings that informed regeneration decisions were communicated to the researchers for security and evaluation. The researcher learned to translate disciplinary jargon into lay language to inform the regeneration while learning and using the language of regeneration professionals in university discussions. This helped to build shared ownership of the project across the two institutions and smoothed communications making for an effective collaboration between the institutions. For further information, see Woolrych and Sixsmith (2013).

The capacity of early career researchers, trainees, and students to implement transdisciplinary working can be built and enhanced through hackathons, knowledge cafés, internships, and individual mentoring. Transdisciplinary research projects also serve as learning opportunities for trainees by exposing them to diverse theories, methods, concepts, and nonacademic contexts that are not covered in their specific disciplinary training (Snow, Salmon, & Young, 2010). Such experiences would help trainees to pursue a more holistic understanding of the real world (e.g., complexity of problems, needs, and perspectives) and strengthen their ability to interact with stakeholders across different disciplines and sectors.

Commercialization Strategies and Plans

When working to research and develop a new product such as a technological solution to a health problem, it makes sense to draw up commercialization plans right at the outset of the project. If the interests of industry partners and needs of the target market (i.e., people who are looking for a solution to a particular problem) are not taken into consideration during the development step, the technology will fall short of successful uptake.

To develop real-world solutions, it is important for researchers to create a commercialization plan at the outset of a project and engage industry partners and potential product and service users in business planning. For example, completing together a business model canvas (Joyce & Paquin, 2016) can enable joint development of precise and concise value propositions (e.g., What problem will the product solve? What is unique about the product?), which is key to successfully (i.e., effectively and efficiently) introducing and also marketing a product or services (Lachapelle, 2018). Understanding the needs, interests, and circumstances of potential users of the product (e.g., their financial situation, accessibility to resources to support their use of the product) will help a research team to create products that are likely to be of practical use to the target market, which in turn will make positive impacts on the lives of the people who make up that market.

Product Innovation Pathway

Key activities that help to generate research outcomes to address real-world problems are reflected in the Product Innovation Pathway summarized in Table 17.1.

Learning More
The following resources might help researches to address real-world problems through transdisciplinary work:

- Barwick, M. (2008). *Knowledge Translation Planning Template*©. http://www.melaniebarwick.com/index.php.
- Barwick, M. (2013). *Knowledge Translation Planning Template*©. http://www.melaniebarwick.com/index.php.
- Diep, J., Sixsmith, J., Kirkland, S., & Panek, I. (2018). *Planning for partnerships between researchers and community organizations: A living document*. Toronto. https://www.oa-involve-agewell.ca/our-reports.html.
- Glandon, D., Paina, L., Alonge, O., Peters, D. H., & Bennett, S. (2017). 10 best resources for community engagement in implementation research. *Health Policy and Planning, 32*(10), 1457–1465. https://doi.org/10.1093/heapol/czx123.
- Joyce, A., & Paquin, R. L. (2016). The triple layered business model canvas: a tool to design more sustainable business models. *Journal of Cleaner Production, 135*(1), 1474–1486. https://doi.org/10.1016/j.jclepro.2016.06.067.

Table 17.1 Product Innovation Pathway (PIP) model—addressing real-world problems

PIP level	PIP description	Key activities
1	Innovative ideas	Engage community members to identify, discuss, and better understand "a wicked problem" they experience in their daily life and to explore research directions, design, and resources that could address the problems (e.g., by attending community events, connecting with community-led organizations, using a world café method) Provide trainees, students, and junior researchers with learning opportunities (e.g., identify research partners, exchange knowledge with diverse community members to explore their problems, needs, and perspectives) via internships and hackathons
2	Planning	Create a mutual understanding of a real-world problem that needs to be addressed in a research team that includes scientists from diverse disciplinary backgrounds, community members, and other key experiential stakeholders (e.g., industry and policy makers) Co-define and co-develop research objectives, visions, and aims with researchers, community partners, and other experiential stakeholders Select research partners with common needs and values and discuss and reach an agreement with them about processes and their roles and responsibilities Develop a knowledge mobilization and commercialization plan in collaboration with research partners Provide trainees, students, and junior researchers with diverse learning opportunities (e.g., learn about and integrate diverse concepts, theories, and methods that are developed by and used in various disciplines and sectors; obtain experience, skills, and knowledge that would build capacity to plan innovative transdisciplinary research projects) via internships and hackathons
3	Development	Engage community members and other experiential stakeholders in discussing and solving problems that may arise during a research project Provide trainees, students, and junior researchers with diverse learning opportunities (e.g., obtain experience, skills, and knowledge that would build capacity to solve problems) via internships
4	Testing in a real-world environment	Use an iterative approach to ensure the progress of a project by seeking diverse perspectives to help the team evaluate whether a project outcome solves a problem in a real-world setting (e.g., by using prototypes of products with potential users, conducting focus groups, surveys, and observations)

(continued)

Table 17.1 (continued)

PIP level	PIP description	Key activities
5	Outcomes and impact	Knowledge mobilization: Collaborate with community partners and other experiential stakeholders in selecting appropriate and relevant information to be conveyed and in identifying effective formats and methods of dissemination for diverse knowledge users and decision-makers who will have an impact on real-world solutions (e.g., social media, presentations at local events, a world café method) Organize and create opportunities to disseminate the project outcomes to relevant key stakeholders to whom research outcomes need to be disseminated in order to create and maximize real-world impacts Provide trainees, students, and junior researchers with opportunities to develop skills and knowledge regarding knowledge mobilization Commercialization: Implement commercialization strategies identified in the planning stage (e.g., consult with community and industry partners on effective strategies for target populations) Co-develop product value propositions with community members and other experiential stakeholders (e.g., seek and incorporate community input) Communicate and negotiate with industry partners on marketing, licensing, and/or distribution of the project outcomes and products Provide trainees, students, and junior researchers with opportunities to engage in and learn about commercialization processes via internships

Key Messages

This chapter describes four strategies for addressing real-world problems through transdisciplinary research projects:

- Community involvement throughout the research process is critical in transdisciplinary research to identify and understand real-world problems and co-develop strategies for translating project outcomes and outputs in order to create positive impacts on real-world problems.
- Research outcomes—whether they take the form of knowledge or products (e.g., services, technology)—need to be mobilized in an appropriate format and disseminated to key stakeholders who can make a real-world impact in a way that reflects the needs and preferences of those stakeholders.
- Training researchers to acquire the knowledge and skills of implementing transdisciplinary research is key to creating and applying innovative solutions to real-world problems.
- Planning commercialization strategies at the onset of the project and collaborating with industry partners are key to translating research outputs into positive impacts on real-world problems.

References

Altman, D. G. (1995). Sustaining interventions in community systems: On the relationship between researchers and communities. *Health Psychology, 14*(6), 526–536.

Barwick, M. (2008). *Knowledge translation planning template*©. Toronto: The Hospital for Sick Children.

Barwick, M. (2013). *Knowledge translation planning template*©. Toronto: The Hospital for Sick Children.

Battersby, L., Canham, S., Krahn, D., & Sixsmith, A. (2017). *Guidelines for en masse interinstitutional relocations of long-term care homes*. Vancouver: Simon Fraser University, Gerontology Research Centre. http://www.sfu.ca/content/dam/sfu/starinstitute/Reports/LTC-Relocations-Guidelines_Feb-2017_DIGITAL(1).pdf.

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., Mihailidis, A., … Martin, S. (2017). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490. https://doi.org/10.3109/17483107.2016.1151953

Diep, J., Sixsmith, J., Kirkland, S., & Panek, I. (2018). *Planning for partnerships between researchers and community organizations: A living document*. Toronto: ON. https://www.oa-involve-agewell.ca/our-reports.html.

Hebb, T., & Thaker, R. (2014). *Partnerships between organizations and business: Challenges and opportunities* (Vol. 2). Ottawa: Carleton Centre for Community Innovation. https://carleton.ca/3ci/wp-content/uploads/R-14-02.pdf.

Joyce, A., & Paquin, R. L. (2016). The triple layered business model canvas: A tool to design more sustainable business models. *Journal of Cleaner Production, 135*, 1474–1486. https://doi.org/10.1016/j.jclepro.2016.06.067

Lachapelle, M. (2018). *Business model design: A strategic approach to analyzing and changing the way you do business*. Chartered Professional Accountants of Canada. https://www.cpacanada.ca/en/business-and-accounting-resources/management-accounting/organizational-performance-measurement/publications/management-accounting-guidelines-mags/performance-management-measurement/business-model-design/bmd-guideline.

Lee, M., Wada, M., Carter, K., Goldman-Hasbun, J., Le, T., … Jung, D. (2018). Conducting a university student mental health needs assessment using a participatory action research approach. *SAGE Research Methods Cases*. https://doi.org/10.4135/9781526446664

Orozco, F., & Cole, D. C. (2008). Development of transdisciplinarity among students placed with a sustainability for health research project. *EcoHealth, 5*(4), 491–503. https://doi.org/10.1007/s10393-009-0210-8

Pohl, C., & Hadorn, G. H. (2008). Methodological challenges of transdisciplinary research. *Natures Science Sociétés, 16*(2), 111–121. https://doi.org/10.1051/nss:2008035

Rittel, H. W. J., & Webber, M. (1973). Dilemmas in a general theory of planning. *Policy Sciences, 4*(2), 155–169.

Sixsmith, A. (2013). Technology and the challenge of aging. In A. Sixsmith & G. Gutman (Eds.), *Technologies for active aging* (pp. 7–25). New York: Springer.

Snow, M. E., Salmon, A., & Young, R. (2010). Teaching transdisciplinarity in a discipline-centred world. *Collected Essays on Learning and Teaching, 3*, 159–165.

Woolrych, R., & Sixsmith, J. (2013). Placing well-being and participation within processes of urban regeneration. *International Journal of Public Sector Management, 26*(3), 216–231. https://doi.org/10.1108/IJPSM-09-2011-0119

Chapter 18
Case Study: Practical Steps in Transdisciplinary Team Working—The Enable-Age Project

Andrew Sixsmith

Large team-based projects often require partners from different disciplines, such as engineers working with clinical or social scientists to develop new health care technologies and solutions. New projects and teams can bring together people who have not previously worked together. Projects may require international teams, where language and cultural issues present barriers to an effective working relationship. Working together in an effective way does not occur *naturally*. It requires a significant amount of effort, cooperation, and management, with all team members being prepared to buy in to new ideas and ways of working. This involves much more than having good communication channels. These kinds of projects represent an important opportunity to work in a truly transdisciplinary way, wherein team members can learn from each other and move toward innovative thinking and solutions in their particular problem space.

This case study focuses on the Enable-Age Project, which was a multidisciplinary and multinational project to examine the role of the home environment in promoting healthy aging. The project brought together leading researchers from various disciplines (including psychology, occupational therapy, sociology, gerontology, and medicine) from five European Union countries. The aim of Enable-Age was to develop a new way of thinking about how the home environment contributes to healthy aging. Although the project comprised some very experienced researchers, the team had not previously worked closely together, and there was a need to build relationships and to work in a truly transdisciplinary way. Enable-Age took the following very practical steps:

Glossary of key terms: It became clear very early on that different partners understood even some of the basic ideas very differently, a problem often associated with transdisciplinary working (see Grigorovich, Fang, Sixsmith, & Kontos, 2019).

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Everyone in the team contributed to developing a glossary that comprised the ideas and concepts that were seen as fundamental to the project.

Training and capacity building: There was significant variation between the national partners in terms of research skills and background. For example, some members were experienced in quantitative methods, while others had expertise in qualitative research. It was essential to do an audit of skills within the project teams, as well as identifying areas for critical discussion and agreement, in addition to building capacity where necessary so that a basis for mutual understanding was created. Specifically, this involved the delivery of training modules on qualitative methods, covering research approaches, data collection procedures, sampling, and ethical issues.

Building a conceptual model: The team developed a conceptual representation of the way various key ideas were interrelated. This started with existing models suggested by team members, but this was expanded and refined to include the wider ideas and objectives of the project and effectively created a transdisciplinary *theory* of the problem space that the team was addressing. The final model helped team members to visualize the project in a holistic way, and this was particularly valuable in connecting different methods survey and in-depth qualitative research within a single framework.

Project manual: Creating a project manual was an essential way to develop effective team-working. As well as the aspects of transdisciplinary working mentioned above, the manual comprised all of the research instruments and a practical protocol for carrying out research in five different countries. Of particular importance was a section on ethical issues, which is crucial when dealing with potentially vulnerable populations.

Impact

The challenges underlying complex, large team projects should not be underestimated. Most importantly, the actions outlined above demand time and commitment from all team members and may require compromises over established disciplinary ideas and even transcend their disciplinary boundaries that can create tensions within a team (Sixsmith, Wada, Grigorovich, Kontos, & Fang, 2020). The idea of "appreciative enquiry" (Cooperrider, Whitney, & Stavros, 2003) is important here, where stakeholders actively engage in constructive dialogue with positive regard for each other to move toward generating new ideas in addition to new ways of working together and finding solutions. Enable-Age put a lot of resources and effort into the early stages of planning and setting up the project. This paid dividends later in the project, allowing the research team to carry out a highly ambitious multi-method and cross-national research program with a minimum of stress and disruption. Enable-Age was seen as a model of good practice, and the *tools* developed in the project, notably the *project manual* and the *conceptual model*, were used subsequently by team members in other major team-based projects.

Key Messages

- Team members need to be prepared to think outside their disciplinary boundaries and jointly develop new ways of thinking about the problem space.
- Teams need to be aware of their strengths and weaknesses and engage in targeted capacity-building, such as bringing in additional expertise or training.
- True transdisciplinary team-working requires strong effort and commitment from everyone involved. Making these efforts early in a project will go a long way to creating successful outcomes.

Project Details and Team Enable-Age was funded by the European Commission involving multidisciplinary teams from Sweden, the United Kingdom, Germany, Hungary, and Latvia. Information on the project and team can be found in Iwarsson et al. (2005, 2007).

References

Cooperrider, D. L., Whitney, D., & Stavros, J. M. (2003). *Appreciative inquiry handbook: The first in a series of AI workbooks for leaders of change*. Bedford Heights: Lakeshore Publishers & Berrett-Koehler Publishers.

Grigorovich, A., Fang, M. L., Sixsmith, J., & Kontos, P. (2019). Defining and evaluating transdisciplinary research: Implications for in aging and technology. *Disability and Rehabilitation: Assistive Technology, 14*(6), 533–542. https://doi.org/10.1080/17483107.2018.1496361.

Iwarsson, S., Sixsmith, J., Oswald, F., Wahl, H.-W., Nygren, C., Sixsmith, A., … Tomsone, S. (2005). The ENABLE-AGE project: a multi-dimensional quantitative and qualitative methodology for European housing research. In Y. Hurol, D. Urban Vespo, & N. Wilkinson (Eds.), *Methodologies in housing research* (pp. 70–90). Gateshead: Urban International Press.

Iwarsson, S., Wahl, H. W., Nygren, C., Oswald, F., Sixsmith, A., Sixsmith, J., … Tomsone, S. (2007). Importance of the home environment for healthy aging: conceptual and methodological background of the European ENABLE-AGE Project. *The Gerontologist, 47*(1), 78–84.

Sixsmith, J., Wada, M., Grigorovich, A., Kontos, P., & Fang, M. L. (2020). The challenges of implementing transdisciplinary working in aging and technology research. In *Canadian Association on Gerontology annual scientific meeting: making it matter: mobilizing aging research, practice & policy*, 18–20 October, Vancouver, Canada.

Chapter 19
Education and Training for Innovation and Impact

Samantha Sandassie and Euson Yeung

The Challenge

Researchers are increasingly under pressure to create real-world impacts. Funding for the so-called *blue sky* project is ever decreasing while innovative and implementable project outcomes have become de rigueur to funding bodies, universities, and governments. For the health researcher, this has necessitated multidisciplinary collaboration, working with not just clinicians, but industry and even with potential consumers. It has often meant performing nontraditional tasks such as filing patents, negotiating product sales, or participating in service design and policy creation. Traditional academic training, while creating the conditions for scientific excellence, does not always prepare the engineer to work with a social scientist, the psychologist to file a patent, or the gerontologist to discuss commercialization or building code amendments. Moreover, with graduates far outnumbering available academic posts, it leaves young researchers unprepared to enter—much less make an impact in—the public or private sectors.

This chapter focuses on five skills and competencies required to create innovative solutions:

- Leadership.
- Project management.
- Working collaboratively.
- Stakeholder engagement.
- Communication.

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Ideally, these skills and competencies should be integrated into graduate education and training. The aforementioned skills and competencies can best be fostered when the principles of adult learning are employed, as represented in Table 19.1 (Taylor & Hamdy, 2013). These principles aid learners to activate their prior knowledge and experience to achieve new goals, ultimately preparing learners to (a) recognize gaps in their own knowledge (Dissonance); (b) generate and examine multiple explanations or solutions (Elaboration and Refinement); (c) make sense of and incorporate new insights (Reflection and Organization); (d) reflect on one's learning process (Reflect); and (e) how to apply new knowledge (Consolidate).

Leadership

Leadership is often undervalued as an important skill in researchers not seeking administrative posts. Leadership is much more than simply *being in charge* by holding decision-making power or by supervising another's work. At its core, it is an individual's capacity to inspire and influence other people to work collaboratively towards a shared vision.

The easiest, and possibly best, way a researcher can foster leadership skills in trainees is by being a good leader. Modelling strong leadership skills can be a powerful stimulus to challenge trainees' existing ideas and conception of a leader and motivate them to identify gaps in their own leadership skills. Encouraging *big picture* thinking through open dialogue is critical to helping learners explore multiple research concepts, ideas, and solutions before making decisions. Too often, trainees are too focused on the minutiae of a project to fully grasp how their work contributes to the overall project mission and vision or to the field at large.

Brainstorming sessions and reflective exercises that guide learners to ask "How does this fit with what I already know?" and "How can this project make a difference?" will help trainees make sense of new information, insights, and perspectives. Be consultative in group meetings and allow space for trainees to pose questions, generate novel ideas, and take turns leading meetings so that trainees are given the opportunity to try out their emerging leadership skills. If possible, incorporate trainee ideas into new projects and allow for increasingly larger leadership roles such as inclusion in stakeholder consultations or mentoring and supervising more junior trainees. Throughout the learning process, trainees should be encouraged to reflect in the moment while completing an activity or task (reflection-in-action) or upon completion of the activity or task (reflection-on-action) so that they can continue to grow their leadership potential.

Table 19.1 Role of Teacher/Mentor in Adult Learning

Adult learning principle	Description of learning principle	Role of the teacher/supervisor/mentor
Dissonance	Existing knowledge and experiences are considered, and challenged or recognized to be incomplete within the context of the field of study.	Provide opportunities for learners to activate and evaluate their existing knowledge and experiences. Provide an appropriate learning environment for learners' knowledge to be challenged.
Elaboration and Refinement	Multiple ideas, explanations, or solutions to a problem are considered and examined.	Help learners explore new possibilities, facts, and concepts, allowing multiple ideas or explanations to be developed and examined. Help learners distill the multiple possibilities or explanations into the most plausible ones.
Reflection and Organization	Learners think about the experience, activity, incident or decision-making process as it unfolds in order to make sense of new knowledge and new ways of organizing their knowledge (reflection-in-action).	Encourage ongoing critical reflection while carrying out an activity or task. Provide a scaffold, such as a conceptual framework, for learners to structure and organize their knowledge.
Consolidation	Learners reflect on the learning process undertaken to examine new insights about the learning process itself and what new knowledge was gained (reflection-on-action).	Promote thoughtful reflection on the learning process undertaken. Provide opportunities to consider and apply new knowledge.
Feedback	Learners receive feedback throughout the learning process.	Provide feedback about learners' ability to articulate or apply what has been learned. Opportunities for learners to reflect on learning experiences. Provide meaningful and timely feedback to the learner.

Adapted from Taylor and Hamdy (2013)

Project Management

Few projects are successful without both strong leadership and excellent project management. Project management is the ability to plan out a project from start to finish by identifying key goals and strategies to accomplish the project mission. It is an umbrella term that incorporates a large number of more specific skills such as critical thinking, strategic focus, and forecasting as well as competencies such as the ability to plan a budget.

Good project managers employ critical thinking skills to consider a variety of possible outcomes from a single action. This *forecasting* allows them to make strategic decisions, prioritize actions and goals, and most importantly approach tasks with a flexibility that is prepared to respond swiftly and effectively to challenges that may crop up along the way. Attempting to commercialize a research product or launch a service, for example, takes a great amount of planning if developing and selling the product and even more planning if entrepreneurship is involved! Strategic planning tools such as the Value Proposition Canvas and the Business Model Canvas (as presented in Chaps. 17, 19, 20, 38, 42) are invaluable to help ground brainstorming and goal setting sessions as well as focus thinking to ensure that actions are relevant to supporting the overall project mission and realistic given the resources (finances, people, expertise, time) available.

Managing a project's financial resources is one of the biggest project management challenges a researcher can face. With increasingly scarce funding, it has become difficult to complete large, impactful research without careful resource management. Many junior faculty members begin their careers unaware of the intricacies of holding a grant, of budgeting, or reporting expenditures and outcomes. Thus, researchers and trainees should work together to identify trainees' working knowledge of managing a research project, and to surface any gaps in knowledge and skill that need to be addressed. For example, trainees should work to familiarize themselves with the terms and conditions of their funding and become familiar with their institution's administrative rules regarding grant management. While the institution will typically handle the setup of independent cost centers, the individual researcher must learn to budget appropriately, use funds only for the project with which they are associated, fulfill any reporting required and the like.

While budgeting can be intimidating, it can be simplified somewhat by using strategic planning tools to brainstorm the many potential costs and setting SMART goals to help determine what costs are actually necessary to make a goal attainable (see Box 19.1). Encouraging trainees to think broadly about the budget will allow them to identify and examine a wide range of expenses and prevent them from defaulting quickly to the most obvious ones. To support trainees in grappling with budgeting, researchers can involve trainees in developing realistic research budget proposals during the grant development phase, tracking expenditures during a project, and with reporting on its completion. While some care needs to be taken with regard to sensitive information, such as colleagues' salaries, such activities would provide trainees the opportunity to apply newly acquired skills and to experience firsthand the financial realities of research. It may be a useful exercise, for example, for a trainee to complete and present a budget proposal for a project idea including a resource list, personnel, material, or equipment costs as well as the *estimates basis*, that is, the justification for the costs included. Trainees could also discuss evidence of risk assessment or consideration of potential challenges that would inflate the project budget as a way for them to build their reflective skills to better anticipate and manage unexpected circumstances. Finally, throughout this process, trainees should be encouraged to think back on the learning process itself to inform further development in project management skills.

Box 19.1 Are Your Goals SMART?

Setting SMART goals helps focus actions towards achieving the project objectives in an effective and efficient manner.

Specific: Are your goals clearly stated and understandable to both you and those working with you? Specific and clearly stated goals help with task prioritization and thus with meeting objectives.

Measurable: How do you know if your goal has been met? Are there easily identifiable metrics attached or a clear indicator of success? Identifying markers of success here will help you to refine your goal further.

Attainable: SMART goals are attainable goals; they are not far-reaching visions or mission statements, but rather smaller landmarks that build towards a greater vision. Consider what it would take to make your goal attainable by brainstorming potential challenges and setbacks.

Relevant: Goals need to be relevant and realistic—consider carefully whether or not goals will help or hinder the overall project vision. Goals need to be chosen and prioritized strategically.

Time bound: Realistic deadlines are critical to ensuring that goals are met efficiently and in an appropriate order of priority.

Learning from Stakeholders

Successful stakeholder engagement transforms the research project such that outcome(s) can be more easily applied and can lead to real-life impact. Although the practice of engaging relevant stakeholders in the research process is frequently discussed, it is also poorly understood and executed. The process of involving individuals or groups who are ultimately affected by the outcomes of health and healthcare research can be a challenging feat; it requires a unique set of skills to engage stakeholders in research endeavors within an increasingly complex healthcare context.

To promote successful stakeholder engagement among trainees, a good place to begin is to have them learn from the stakeholders themselves about stakeholders' perspectives on the research in question. Listening to stakeholders' narratives not only activates and challenges trainees' previous conceptions of the stakeholder group, but also helps them understand the possible impact the research will have on individuals and/or groups. Once trainees have had opportunities to consider their existing knowledge and knowledge gaps, trainees should be encouraged to think broadly about stakeholder engagement beyond the mechanics of participant recruitment. For example, trainees could consider multiple ways that stakeholder engagement would be beneficial to the research process, such as customizing communication strategies and/or translating profession-specific or technical language to more easily understandable terms. Trainees may also benefit from consulting widely within the identified context to determine all of the individuals and/or groups who will be affected by the research. Broad consultations with stakeholder groups can help trainees consider multiple ideas and solutions, including the root cause of the issue that the research is tackling. In order for trainees to make sense of insights from these consultations, offering a conceptual framework for their reflection will provide a structure for trainees to organize their previous and new knowledge.

Because stakeholder engagement is a relational practice that must be carefully nurtured over time, learners should have opportunities to reflect deeply on their interactions with stakeholders both as the interactions unfold and upon completion of the research. This way, new insights and perspectives about the stakeholder group(s) and about the learning process undertaken can be applied to future research endeavors. For example, trainees could be guided to engage in thoughtful reflection on how and when to initiate communication with stakeholders, how to adapt their communication(s) as the stakeholder engagement process unfolds, determining the most appropriate mix of stakeholders, and how to develop and maintain a healthy and productive relationship with stakeholders.

Learning How to Work Collaboratively

One of the persistent challenges in research training is to strike a balance between developing individual research expertise while building trainees' capacity to collaborate within a team. As in other disciplines, the consequences of poor collaboration can be costly, leading to miscommunication and mistrust, unresolved conflicts, inefficiencies, and outcomes that do not align well with the intended goals, just to name a few. Fortunately, many of these consequences are avoidable if the principles of collaboration can be learned, applied, and monitored throughout the research process.

To equip trainees to work collaboratively, researchers should first recognize that all trainees come with their own understanding of collaboration, stemming from both positive and negative experiences. Regardless of their level of fluency in working with others, trainees' previous knowledge and experience in this regard must be brought to light in the context of the research being conducted. For example, allowing potential perceived hierarchies (disciplinary, professional, etc.) to be discussed may help trainees recognize the risks that hierarchies may bear on team work. Modelling exemplar collaborative behaviors is another practical way to challenge trainees' pre-existing ideas about how to work in a team.

Because collaborative work requires highly complex group processes, researchers could provide trainees with a conceptual framework or guiding principles on managing collaborations. Using this framework, ongoing reflective practices such as reflective writing about one's assumptions, interpretations, and/or beliefs, could help trainees uncover misperceptions or gaps in one's knowledge or perspectives that can threaten successful collaborations. A deep understanding of and respect for team members' perspectives is another critical factor in successful collaborations. Thus, trainees would benefit from learning to listen to team members and to provide constructive feedback to each other. To this end, adequate time must be set aside to allow trainees to practice active listening, respectful communication, and giving and receiving feedback.

Learning Multimodal Communication

As discussed above, good communication skills are invaluable to successful collaboration and stakeholder engagement. Strong communication skills are also necessary to maximize the impact of your work by conveying the right messages clearly to the right audience. Too often, researchers focus only on communicating well with each other, emphasizing, for example, the importance of conference presentations and academic publications. This internal focus, unfortunately, has the tendency to leave project outcomes and outputs within academic circles and decrease dramatically their chance at producing impact; while a research paper arguing that increased stair widths would result in significantly fewer injuries is interesting, informing decision-makers such as government, industry, and consumer groups would be a more useful approach.

There are a myriad of ways in which communication is key to developing and delivering a strong, innovative project that makes a real-world impact. Indeed, knowledge mobilization strategies include actions taken at the very beginning of a project, such as stakeholder engagement to help develop the project idea to knowledge exchange activities like café scientifiques that occur throughout the project life cycle (see Chap. 5 for a more detailed discussion of knowledge mobilization). As is the case with stakeholder engagement, trainees need to learn how to adapt their style of communication to different audiences. This means that trainees must first understand the needs of diverse audiences by asking "What does this mean to different audiences?" and "Why does the audience need to hear this message?" Researchers should therefore provide trainees with ample opportunities to plan and execute a wide range of communication strategies including traditional written and oral forms as well as other creative forms of communication.

Table 19.2 Product Innovation Pathway model

Product Innovation Pathway model (PIP)—Training and education for innovation and impact				
PIP level	PIP description	Key activities	Sample domains of training[a]	Adult learning principle that supports training
1	Innovative ideas	Think about potential challenges from logistics to determining IP. Encourage trainees to brainstorm and think creatively about a project's vision and mission. Write reflectively to imagine a variety of scenarios about your project's potential impact.	Leadership Stakeholder engagement	Dissonance Elaborating and Refinement Reflection and Organization
2	Planning	Introduce trainees to strategic planning and management tools such as the business model canvas. Create and complete SMART goal worksheets in group or lab meetings. Jointly develop a shared vision and mission. Complete emotional intelligence or work style assessments to help develop the self-awareness to work and communicate better with colleagues and stakeholders.	Project Management Working collaboratively	Dissonance Elaborating and Refinement Reflection and Organization
3	Development	Demonstrate the importance of collaboration, stakeholder engagement, and co-creation via knowledge sharing activities such as café scientifiques or symposia. Actively involve trainees in planning and executing these events. Visit and revisit SMART goals and other strategic planning tools as the business model or value proposition canvasses.	Project Management Working collaboratively	Dissonance Elaborating and Refinement Reflection and Organization
4	Testing in real-world environment	Development actions need to continue at this stage as well. Stakeholder engagement is key to successful testing and (re) iterations.	Stakeholder engagement	Dissonance Elaborating and Refinement Reflection and Organization
5	Outcomes and impact	Create or re-create a thorough knowledge mobilization plan. Contact your institution's innovation or commercialization office for support. Consider carefully your audiences, identify your gatekeepers and key decision-makers in order to properly tailor your message.	Communication	Reflection and Organization Consolidate Feedback

[a]The domains of training listed are examples of a range of possible domains.

It is important to remember that communicating project outcomes is not limited to public talks. Communication strategies need to be implemented for various audiences, including community and clinical partners, the general public, and government agencies, just to name a few. Thus, researchers should help trainees become familiar with a variety of output strategies and the audiences to which they are best suited. Providing opportunities to tailor a message to a particular audience is an important skill that requires the research, critical thinking, and planning skills discussed in the project management section.

To this end, researchers could provide guiding principles that help trainees construct and execute a communication strategy. First, ask the trainee to set a goal for communicating with the target audience; what are you trying to achieve or change? Second, the trainee must learn to describe their audience(s); who are the key stakeholders, the gatekeepers, or decision-makers? Third, it is crucial for trainees to identify what these people believe about your topic and what they consider important. Last, trainees must consider how to frame the message. Too often, for example, we overemphasize our methods or the minutiae of our data sets rather than communicating the big picture and practical or usable solutions that stem from them. Here, it would be helpful to brainstorm the possible ways your audience could react to your message to select the best frame and channel to influence change.

Regardless of the communication strategy, strong empathy and adaptive behaviors are needed to convey complex concepts to a lay audience while active listening skills are necessary to fully appreciate and incorporate the ideas generated. Central to developing effective communication skills is timely and constructive feedback. Thus, researchers must take advantage of every opportunity to give guidance to hone these skills by encouraging trainees to articulate and apply the lessons learned about communication to further improve upon these skills in the future.

Finding Support

- **Courses and workshops:** Many institutions, professional bodies, and employers offer professional development courses and workshops that offer researchers and trainees the opportunity to further hone many of the *soft skills* discussed in this chapter. More formal courses in leadership, lay communication, and project management are also offered by continuing education programs and may provide more rigorous, credit-based training such as Lean certifications.
- **Institutional departments:** Your institution's research finance office or *innovation* offices or departments can provide a wealth of information on grant management and budgets and can guide researchers through commercialization or knowledge mobilization activities.
- **Online resources:** Alex Osterwalder and his team at Strategyzer have popularized and made available their Business Model Canvas and Value Proposition Canvas for free download at https://strategyzer.com. The Global Leadership Foundation hosts a free Emotional Intelligence assessment that can aid in devel-

oping self-awareness at https://globalleadershipfoundation.com/geit/eitest.html. Dr. Melanie Barwick has developed a knowledge translation planning tool at http://www.melaniebarwick.com/training.php.

- **Mentorship:** Senior colleagues, entrepreneurs, and others who have tread a similar path are a fount of knowledge and wisdom.

Learning More

- Anderson, R. J., & Anderson, L. E. (2010). Professorial presentations: The link between the lecture and student success in the workplace. *Academy of Educational Leadership Journal, 14*(1), 55.
- Kerzner, H., & Kerzner, H. R. (2017). *Project management: A systems approach to planning, scheduling, and controlling* (12th ed.). New York: Wiley.
- Lussier, R. N., & Achua, C. F. (2015). *Leadership: theory, application, & skill development* (6th ed.). Nashville: South-Western College Publishing Group.
- Mayer, J. D., & Salovey, P. (2004). What is emotional intelligence? In P. Salovey, M. A. Brackett, & J. D. Mayer (Eds.), *Emotional intelligence: Key readings on the Mayer and Salovey model* (pp. 29–60). Port Chester: National Professional Resources.
- Todoroff, C. (1997). *Presenting science with impact: presentation skills for scientists, medical researchers, & health care professionals*. Trifolium Books Incorporated.

Key Messages

- Creating real-world impact requires much more than just scientific excellence.
- Researchers and trainees are increasingly challenged to think outside the proverbial box and perform tasks not usually associated with academia's *ivory tower*.
- While the rigors of academic programs may not allow much time for formal training in professional, personal, and interpersonal development, there are numerous ways in which researchers can structure their supervision and mentorship to foster these key transferable skills.
- Use of adult learning principles can help to structure training efforts to meet this goal.

Reference

Taylor, D. C. M., & Hamdy, H. (2013). Adult learning theories: implications for learning and teaching in medical education: AMEE Guide no. 83. *Medical Teacher, 35*(11), e1561–e1572. https://doi.org/10.3109/0142159X.2013.828153

Chapter 20
Case Study: Teaching Innovation in Action—the Case of the AGE-WELL EPIC Summer Institute

Samantha Sandassie and Euson Yeung

Researchers and trainees are increasingly tasked with creating innovative solutions to real-world problems often without the education and training required to mitigate the challenges of (1) working in transdisciplinary ways; (2) co-creating; (3) commercializing; (4) participating in service delivery model design; or (5) policy creation. Postsecondary institutions have begun to provide support in some of these key domains in the form of noncredit workshops and lectures, but these remain generally unintegrated, disparate, and didactic. On the other hand, externally offered hackathons and the like while allowing participants to engage actively and practically with these domains tend to poorly prepare participants who are unfamiliar with the domains and discourage those from disciplines where hackathons are not a norm.

The AGE-WELL Summer Institute provides an intensive, 1-week project-based learning experience for trainees to both receive training *and* engage actively and practically with these domains to be better equipped to deal with the challenges of transdisciplinary working, co-creation, commercialization, service model design, and policy development. Building on Taylor and Hamdy's (2013) work on adult learning principles, the Summer Institute ensures that trainees work through the learning process from identifying knowledge gaps to receiving feedback over the course of a week of didactic instruction, interactive workshops, and small group work in order to co-create solutions (technology, service, policy, or a combination of these) that can help to improve the lives of older adults or caregivers.

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Working in Transdisciplinary Ways

Working in transdisciplinary ways (Boger et al., 2016) can help ameliorate the disciplinary limitations that hinder researchers' abilities to solve *wicked* problems by focusing more directly on what is needed to solve the problem itself, rather than focusing on the usual requirements, structures, and methods of their disciplinary approaches to the problem. Summer Institute teams are comprised of six individuals from different disciplines and educational backgrounds, often crossing the boundaries of hard sciences and social sciences. Working as a team can be very difficult, so trainees are encouraged to acknowledge and share the gaps in their own knowledge and their strengths, their expectations for the week, and how they work best. Drawing on the principles of teamwork, teams are reminded that, while a natural or appointed team leader could exist, they all share the ownership of having to meet Summer Institute objectives and would have to practice clear communication, active collaboration, time management skills, flexibility, and the ability to think on their feet.

Engage with Stakeholders

The Summer Institute is focused on co-creating possibilities with both other disciplines *and* stakeholders such as older adults and caregivers. Further to this, teams are introduced to the tenets of user-centered design such as the importance of understanding the potential user and the user experience, as well as how to involve the user throughout product design and development. Teams were then matched with an older adult or caregiver to inform their approach in identifying a problem and solution. This approach provides an opportunity for trainees to recognize the limitations of, and challenge, their existing knowledge and perspectives based on the lived experience of older adults and practitioners involved in delivering services. The integration of stakeholders as part of the team also ensures that trainees can explore and validate brainstormed solutions in a safe space with mentors who challenge assumptions, help make connections between old and new knowledge, and encourage iterative thinking to choose or design the most appropriate solution.

Design Practical and Innovative Solutions

Through a series of lectures, paper-based prototyping workshops, and close mentorship, trainees are introduced to the challenges of designing their solution through iterative design activities and stakeholder engagement or consultation. Trainees are asked to identify a *problem* and refine their *need statements* to emphasize a deeper understanding of the myriad issues underlying the problem identified. Next, trainees are encouraged to check in with their stakeholder to better understand *how* to solve the problem identified rather than simply checking whether their solution is acceptable or not. From there, trainees outline a number of possible solutions, referring back to the earlier workshop stages to ensure that the solution chosen was the most appropriate intervention for the problem, and the stakeholders, identified. This method ensured that those with little or no experience in designing technologies for older adults were encouraged to think critically about their ideas, its utility, and benefits.

Explore and Engage in Nontraditional Knowledge Mobilization

The Summer Institute defines *solution* as a technology, service, or policy. Trainees are actively encouraged to explore nontraditional academic knowledge mobilization opportunities such as commercialization and policy formulation. Teams are given the space to reflect on the experiences and learnings they have encountered during the week thus far and organize their ideas using tools such as knowledge mobilization plans and the business model canvas (For more on these planning tools see Chaps. 5, 47 on knowledge mobilization and Chap. 19 on education and training for innovation and impact). In addition, teams receive instruction, coaching, and feedback throughout the week on their ability to communicate their solution's potential in a persuasive and engaging manner. The Summer Institute experience culminates in a 5-min pitch competition where teams present their solutions, highlighting their practical value and potential for impact. Teams receive feedback from experts, as well as continued support post Summer Institute to continue developing their concepts into market-ready products.

Outcomes and Impact

The Summer Institute structure successfully introduces trainees to the tenets of transdisciplinary working and encourages them to acknowledge the limitations of their discipline and the valuable contributions of others (both expert and stakeholder). We believe that this emphasis contributed greatly to the fact that every Summer Institute has resulted in teams that have gone on to develop and sell or commercialize their solutions.

Key Messages
- The Summer Institute utilizes theory-informed pedagogy to engage trainees in a transformative learning process.
- The success of the Summer Institute's structure is largely attributable to ensuring trainees' assumptions and their expertise are challenged by those outside of their discipline and academia in general.
- Providing space and opportunities for ongoing critical reflection ensures that trainees are better able to structure their knowledge, consolidate new knowledge, and apply these in effective ways.

Project Details and Team The AGE-WELL Summer Institute is offered annually to trainee members of the network. It was developed by network staff in collaboration with researchers and trainees from the University of Toronto and Wilfrid Laurier University. Additional details may be found on the AGE-WELL (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life) website (https://agewell-nce.ca/training/summerinstitute) and by contacting training@agewell-nce.ca.

References

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., Mihailidis, A., … Martin, S. (2016). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490. https://doi.org/10.3109/17483107.2016.1151953

Taylor, D. C. M., & Hamdy, H. (2013). Adult learning theories: Implications for learning and teaching in medical education: AMEE guide no. 83. *Medical Teacher, 35*(11), e1561–e1572. https://doi.org/10.3109/0142159X.2013.828153

Chapter 21
Building an Inclusive Research Culture

Debbie Baldie, Caroline A. W. Dickson, and Judith Sixsmith

The Challenge

Research happens in all sorts of different places, the university setting and research institutes being key locations. Professional practice settings are also locations where research, particularly applied research, happens. For example, the judicious use of research and continual evaluation of practice are critical to achieving high-quality health care and higher education provision and are integrally linked to the research capacity and capability of the workforce. However, not all workers in such settings are research active and, when pressed to *do* research, can identify a range of barriers, stating:

> "I don't have time!"; "My teaching workload prevents me doing research!"; "The priorities don't match with what I am interested in!"; "I wouldn't know where to start!"; "What I do is not worthy of research."

Such attitudes create environments that can be described as research sparse at best and research averse at worst. What, then, prevents the development of a positive research culture? What enables individuals, teams, and organizations to develop a healthy attitude toward research and increase their research activity and impact? These key questions particularly preoccupy academic and research leadership in practice, in their attempts to build research capacity within their organizations.

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Often, active engagement with research is poor to nonexistent in professional roles. While using evidence to underpin practice is fundamental to "being" a professional, studies repeatedly emphasize the lack of time and support practitioners have to access and use literature, as well as appraise evidence. This is, of course, variable across professions and somewhat dependent on job designs. In health, for example, doctors in Scotland have protected time to undertake research or scholarly activity within their job plans (up to 10%). Nurses, on the other hand, working in the same system have 2.5% of their time allocated for all of their continuous professional development per year, including research time. Clearly institutional barriers are hugely important to consider when trying to develop a flourishing research environment.

The pace of change in public service and higher education provision and the constant demand for immediate or early improvements in performance also compromise the ability of professionals to engage with research. This can mean that systematic reviews or careful, evidence-informed, co-designed robust, and reliable evaluation of change can be replaced with indiscriminate implementation of individually sponsored *good* ideas or heavily marketed or policy-driven suggestions.

Equally, in health and social care practice settings, a tendency to use simplistic models for quality improvement effectively disregards the complexity and constant movement in cultures and contexts within which practice takes place. In these instances, research results are often impractical or unworkable when applied to real-world problems. In health care, for example, the scrutiny model for enhancing quality of care and health outcomes means most efforts are spent generating evidence of good enough practice rather than on improving and innovating practice.

In many workplace settings, including academia, research tends to remain the privilege or responsibility of relatively few people. This chapter explores how this situation can be transformed turning research reluctant environments into flourishing research cultures using the following key ideas:

- Building an effective infrastructure.
- Growing teams using a recognized philosophy and associated methods.
- Building research into everyday work and role expectations.
- Providing personalized support to individuals.
- Building effective partnerships to grow confidence, increase research networks, and enrich the quality of research.
- Making time and creating a positive writing culture.
- Reflecting on and celebrating progress.

Key Ideas

Building an Effective Infrastructure

Without an effective infrastructure that supports people to work together to consider research ideas alongside their workplace concerns, research can be perceived by many as a luxury and separate from core work. Constructing an infrastructure of supportive learning (1) facilitates collective understanding of what is possible and (2) builds belief among individuals that they can undertake research that is meaningful to them and their practice. Explicitly formulating the necessary space, place, values, and research focus in group discussions is a primary step toward such development. Then using this environment to attract like-minded people is critical to building flourishing research environments. When the space (e.g., time), place (virtual or real), values (e.g., honesty, sharing), and research focus (e.g., health equity, person centeredness) are mutually agreed upon within the group, then ownership of the research becomes a reality with people working with and for each other in the interests of shared enterprise. This enables people to talk about their research, their interests, and ambitions, find common ground, and develop shared research aims. Once internal identity has been achieved, then reaching out to wider potential partners to develop research ideas, project plans, and program grants can happen (see Chaps. 17, 21). In turn, this expands the capacity and capabilities of the research group in a safe and supportive infrastructure leading to:

- A broadening of knowledge of potential funding resources.
- Methodologies and methods.
- Publication and other impact routes.

Once identity and purpose have developed and supportive staff are in place, then research can become visible within performance enhancement reviews, thereby making it part of the everyday work of the organization (see Box 21.1).

Box 21.1 Making Research Visible in the Workplace
In the Nursing Division in Queen Margaret University, a workload model was developed that profiled time for research and scholarly activity with the explicit and shared aim of growing research capacity and capability, thereby enhancing the quality of the work and reputation of the division. Over the space of 4 years, the division has moved from a position of no nurse lecturers being returned in the national research assessment process to eight returns. In the same period, the number of candidates, including team members, undertaking doctoral studies rose from 8 in 2013 to 40 in 2017, publications have increased from 14 to 43, and research income has increased 75-fold in the same period. The growth in these outputs endorses the importance of a supportive infrastructure.

Growing Teams Using a Recognized Philosophy and Associated Methods

Sustainable change in any professional practice culture requires a systematic, evidence-informed process. Without this there is little to help team transformation toward being research active, and leaders struggle to get people to "buy into an idea" that ultimately is not shared by all (McCormack, Manley, & Titchen, 2013). As Senge (2006) argues, cultural change happens from *within*. Ensuring workplaces create a context that enables all persons to flourish is key to transformational change. Theory U is helpful here (see Box 21.2), being a transformational change model

Box 21.2 Theory U Explained
The principles of Theory U can help people working in complex systems to break out of (1) previously unproductive ways of thinking and/or (2) decision-making that prevented them considering what life and their customers, clients, and audiences want and need from them. It acknowledges that all culture change requires change within persons, changes to how they reason, and, finally, changes to how they then act. Unlike other change theories, it recognizes the need for people to let go of previous patterns and ways of thinking in order to generate new ideas, new ways of reasoning, and new cultural norms. Theory U suggests that such transformation takes time and is limited by individual and collective voices of fear, judgment, and criticism. Here, the key idea is that change moves from ego (individual) to eco (collectives).

(and a global movement) that supports teams and individuals to avoid the need to get people to *buy-in* to new ideas or ways of working. Instead it focuses on helping teams to create their own environment that encourages a healthy critique of individual and group practices (Scharmer, 2018).

Promoting change requires people to (1) examine and develop themselves as human beings and (2) connect to others in ways that are consistent with respecting collective values and aspirations. When this is applied in organized ways, it can help optimize individual and team performance (see Box 21.3). Key steps in this process include discussion and action around:

- Co-creating a desired future (figuring out what life is calling you to do) that addresses each person's aspirations, values, and beliefs.
- Sensing what internal and external factors are preventing the pursuit of collective and individual visions.
- Prototyping new ways of being and doing.
- Embedding new and more productive, effective, and fulfilling practice norms, rituals, and behaviors.

Building Research into Everyday Work and Role Expectations

Lack of time is always an issue in conjoined academic and practice roles. Under time pressure, it is easy to deal with practice situations that are imminent and urgent and neglect longer-term research-oriented goals. If team members are to be researched active, it is crucial that time for research is scheduled into job plans. In hierarchical cultures, divisional heads can agree on the level and amount of research time with individuals, but this can invite jealousy and a sense of unfairness when some people are allocated more time than others. To avoid this, a system of shared governance (concerned with empowerment) can be introduced. Using the principles

Box 21.3 Framing Cultural Change
In Queen Margaret University in Scotland, the Division of Nursing drew on person-centeredness, human flourishing, and Laloux's (2014) work on reinventing organizations to help define their desired future. This helped make explicit their shared intention to engage in *ways of being* (researching) that were grounded in respect for personhood with the intention of developing a flourishing culture (McCormack and McCance 2017). They also drew on the philosophy of critical social science and intentionally focused on and worked to become increasingly empowered, self-determining, and to share decision-making. In this way, they strove to create conditions that support human flourishing. The desired future and values that would underpin their journey were made explicit in the Divisional Strategy (2015, 2018). Time was created to regularly reflect on progress (using Theory U and critical creativity methods) and plan next steps toward achieving their vision. These consisted of three-team away days per year, weekly *open forums* to discuss issues relevant for the Division, and six weekly divisional meetings with an hour dedicated to a Habermasian conversational space.

of shared governance, the Nursing Division and Queen Margaret University (QMU) took a collective approach to both workload planning and the development of a research culture. A Research and Development Group was created, and every staff member became a member of one-shared governance group. The Research and Development governance group hold responsibility for key research objectives supporting research activity to meet explicit aims. A key strategy to enhance research activity, outputs, and impact was the establishment of a Clinical Academy. Such partnerships are recognized internationally as critical to developing knowledge in ways that are immediately accessible and used to improve practice. Each team member sought to strengthen clinical-academic relationships and promotes collaborative partnerships for research, as well as teaching, learning, and clinical practice. Focused attention on research also helped people widen their research networks, opportunities, and subsequent research activity. Overall, the program of work has supported people to become more research and scholarly active and encouraged them not to separate it from the work of the division but to view research as an instrumental and core activity built into everyday work patterns.

To help people see themselves as researchers, a dedicated approach is needed which specifically focuses on building researcher identities. This involves consideration of what life was calling them to do in their roles; what they really want for their individual and collective selves; and what is getting in the way of them achieving their individual and collective aspirations and then working collaboratively together to seize opportunities and overcome challenges. Doing so helps people recognize the contribution of research to their workplace and to consider and develop plans for their research/scholarly activity to be commensurate with the overall organizational strategy and work plan.

Providing Personalized Support to Individuals

It is important that individuals are helped to connect their own aspirations to a wider vision and work plan if they are to move to a flourishing workplace. Typically this is done through standard procedures of staff appraisal that can feel soulless and disconnected from a sense of personhood. One way to overcome that is to allow them space for deep thinking, create an opportunity to validate their activity, and indicate how their work makes meaningful contributions to their team, its outputs, and reputation and—more widely—for knowledge generation. This moves away from more corporate processes to more person-centered processes of research activity evaluation.

Practices that can help to make this shift include keeping shared values visible in working practices, knowing each other (in terms of skills, expertise, knowledge, etc.), establishing of mentors and triadic advisors, and inputting from experts within and without the organization. Each team member agrees personal objectives relative to their role and longer-term ambitions that, for some, means a realignment of roles. Moving intentionally toward Laloux's (2014) Teal organization where power and decision-making are shared, people can be encouraged to seek skilled mentorship to enable support for their individual developmental needs and to help them reflect on and address practice issues that get in the way of their engagement in scholarly or research activity. *Triads* can also be established between members of the team to provide a space for high support and high challenge extending to a peer performance enhancement review. Setting up and resourcing regular learning sessions on grant writing, writing for publication and specific methodologies also help team members engage in learning and development that address their own needs and research foci.

Building Effective Partnerships to Grow Confidence, Increase Research Networks, and Enrich the Quality of Research

It is well understood that effective research teams have extensive and networks of people they work with to secure research funding and undertake research. Practice partnerships between service providers and academics create opportunities to release practice knowledge that is embedded in experience, is embodied, and focuses on maximizing the potential of people. The Clinical Academy model supports people to explore their existing networks and establish or grow partnerships with a clinical area or third sector organization. In the context of the Nursing Division at Queen Margaret University, using the Clinical Academy model has led to 31 honorary appointments including 6 Associate Professors with 3 being international partnerships. The Clinical Academy has created opportunities at local, national, and international levels to examine the practice context and explore how research and quality improvement can work more closely together. Fundamentally this has led to practitioners and academics working together on shared research and practice topics as advocated by the Willis Commission (Willis, 2015).

Making Time and Creating a Positive Writing Culture

In research, as well as practice roles, it can be difficult to prioritize writing. Writing often gets relegated to evenings, weekends, and early mornings. It is not only important to dedicate time for writing by creating a supportive culture that enables people to grow in writing confidence and skill. Two initiatives that have worked in the Nursing Division have been the establishment of a dedicated time and space for writing each week alongside writing retreats. A weekly place and time was created at a time that was unlikely to be interrupted by another pressing activity. It was also a space where people could share and ask for feedback on their writing. This space was used to write papers for publication, book chapters, grant proposal writing, curricula documents, final reports, and academic coursework. This made a space for all, regardless of their time allocation for scholarly or research activity, for an uninterrupted writing time and thereby highlighted the importance of the activity. Resources for writing retreats can be funded at an organizational level or through self-funding. Having a person leading the retreat can also ensure productive time is protected and used efficiently. Using writing methods such as the Pomodoro Technique, a time management approach (goal setting, time limited—usually 25 min—writing intervals, followed by short breaks and reflection) can help with confidence building and writer's block (Cirillo, 2018). Understanding your own writing preferences is really important to enjoying the experience of writing. Other ways to circumvent writer's block or procrastination are to talk through the idea with a colleague and begin writing without considering structure, grammar, or punctuation. Set a doable writing schedule (start small, take small steps) and identify the time, place, and people that help you write best. Turn off your technology's notifications and remember to reward your achievements! These techniques can be used at home or during writing retreats. In fact, mini retreats where staff schedule time to work at home with others (perhaps extending the invitation to non-academics) can be not only effective but fun.

Reflecting on and Celebrating Progress

Too often teams keep busy trying to accomplish strategic objectives, using action trackers and project planning to consider how they are progressing, while there is nothing wrong with being organized and keeping track of progress. However, such a technical approach offers limited opportunities to uncover cultural norms and personal ways of being that are either hindering or enabling progress toward a vision of a flourishing workplace. Technical approaches leave little room for the acknowledgment of peoples' valued competencies, i.e., those attributes and skills people in the team have that are unique to them but which offer a diverse richness to team development.

To bring a more flourishing approach to accomplishing objectives, the research team can intentionally make a meeting space to reflect and celebrate individual and collective progress, perhaps in monthly meetings and team events. At QMU, time is taken to step back and take stock, as well as repeatedly and systematically reflecting on progress and figuring out how to address collective obstacles as well as consider the personal implications for individual work patterns. Such meetings are focused not only on the practical issues but also on the cultural norms as well as embedded beliefs and values. To ensure recognition within the team, they include Champagne Moments to learn about, celebrate, and respect each other's achievements (see Chap. 9).

Learning More

- To learn more about how to engage in transforming cultures read: Laloux, F. (2014). *Reinventing organizations: a guide to creating organizations inspired by the next stage of human consciousness.* Brussels: Nelson Parker.
- To read more about Theory U and alongside the references given in the reference section below, there are useful resources on Otto Scharmer's website: http://www.ottoscharmer.com/.
- To find out about person-centered care in practice read: McCormack, B., and McCance, T. (Eds.). (2017). *Person-centred practice in nursing and health care: theory and practice* (second ed.). Chichester: Wiley Blackwell.
- Queen Margaret University provides a development program that supports people to gain skills in facilitating person-centered cultures—look out for this annual development opportunity at this link: https://www.qmu.ac.uk/study-here/continuing-professional-development-cpd-courses/cpd-courses-folder/facilitation-for-the-development-for-person-centred-cultures-equivalent-to-a-single-module/.

Key Messages

Building research activity is often seen as growing capacity but is as much about changing a culture. Critical to culture change and team success is:

- Developing a challenging and exciting vision that everyone owns and can engage with.
- Paying attention to people and their personal desires.
- Creating safe spaces where people can reflect on their strengths and get support without judgment.
- Developing skills and offering exposure to different research and scholarly activities builds confidence and competence.
- Profiling research and/or scholarly activity time in job plans is critical to research and scholarly activity becoming the norm.
- Pausing, reflecting, and celebrating are critical to building momentum and commitment.
- Skilled mentorship helps grow skills and confidence in novice researchers.

References

Cirillo, F. (2018). *The Pomodoro technique: The life-changing time-management system*. London: Random House.

Laloux, F. (2014). *Reinventing organisations: A guide to creating organizations inspired by the next stage of human consciousness*. Brussels: Nelson-Parker.

McCormack, B., Manley, K., & Titchen, A. (Eds.). (2013). *Practice development in nursing and healthcare* (2nd ed.). Chichester: Wiley-Blackwell.

McCormack, B., and McCance, T. (Eds.). (2017). *Person-centred practice in nursing and health care: theory and practice* (second ed.). Chichester: Wiley Blackwell.

Scharmer, O. (2018). *The essentials of Theory U: Core principles and applications*. Oakland: Berrett-Koehler Publishers.

Senge, P. M. (2006). *The fifth discipline: The art and practice of the learning organization*. London: Random House Business.

Willis, P. (2015). *'Raising the bar. Shape of caring': A review of the future education and training of registered nurses and care assistants*. London: HEE.

Part III
Designing Together

Mei Lan Fang

Overview

Expectations on how knowledge is produced in research and development have evolved over the last 20 years (Polk, 2015). These changes are reflected in broader science policy which has seen a gradual shift toward removing social and structural barriers between academia and the lay community, when creating new knowledge and developing new science. This more recent vision for research, development, policy, and practice is one that encourages open scholarship and the co-production of knowledge through active encouragement of public engagement in research and research governance (Canadian Institutes of Health Research, 2004). As part of this new vision, there is a strong endorsement for more equitable participation of all those involved and impacted by the research, whether they are from political, industry, or public sector or whether they are from an academic or lay community (Maasen & Lieven, 2006). This is crucial for increasing and operationalizing accountability of people who create knowledge and those who seek to benefit from it.

Importantly, adopting a process of co-design and co-production is important for generating research impacts. A key aspect of this way of working in research is the strong recognition that the value of research and development is only truly realized through the impact it has on individuals, communities, and societies at large (Research Councils UK, 2014). Research impact is the demonstrable social and economic contribution achieved through important developments in methods, theory, and applications in the real world. It is only through the practice of co-design and co-production that such developments can materialize into useful products-benefiting individuals, communities, organizations, and nations (Grigorovich et al., 2019).

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However, the implications for achieving this have conceptual and practical implementation challenges that stem from the joining of knowledge, which has traditionally been produced differently and in isolation across the scientific community. While some challenges can be addressed through guidance and requirements for research impact at the national level, it is only through individual practitioners, researchers, and professional networks that new cultural practices become embedded, integrated, and normalized in everyday work contexts (May & Finch, 2009).

To help researchers overcome some of the barriers of co-design in their day-to-day practice, this section introduces chapters written and developed by those who use co-design processes in their roles as academics, community liaisons, industry professionals, and clinicians to provide some practical guidance and support for research co-design and co-production.

Content Overview of Chapters

The following section presents eight chapters; alongside these chapters are three case studies and two learning activities that highlight the nuances, complexities, and value of co-creation approaches while providing key methodological features and strategies for enhanced research and development. As with any type of research approach, there are several sequential steps necessary for creating optimal conditions for co-design and development. When embarking on new research, the first step and the often most important step is to undertake an assessment of the current state of knowledge. Doing so will enable a better understanding of where gaps in knowledge and evidence exist.

To begin, MacGillivray in Chap. 22 discusses the ways in which a research team can conduct a robust and rigorous review of existing knowledge to inform the initiation of new research. Key ideas addressed in this chapter include the:

- Importance of understanding how to plan a literature review and the key steps involved
- Need for clear and transparent methods to be used to search for and appraise the literature
- Value of involving *users* in preparing and conducting a literature review

MacGillivray's chapter provides practical guidance on how researchers can determine the type of review required, and subsequently co-design a protocol with key stakeholders; implement a review protocol in a transparent, reproducible, and rigorous manner; and integrate the interests and perspectives of key stakeholder groups.

Next, as co-production requires careful planning to ensure the involvement of all parties affected by the health innovation, Astell and Fels provide key ideas on how researchers can co-produce health innovations with their intended recipients or users of new products or services. This chapter explains the:

- Prerequisites for co-production
- Selection of appropriate user-centered methods

- Co-analysis of data
- Integration of results into design

Following MacGillivray's guidance on conducting reviews, Astell and Fels discuss the importance of integrating a user's and/or a recipient's knowledge and expertise into the research's design; creating a friendly environment that facilitates everyone's voices; reviewing various co-production methods to identify the right one(s) for your purpose; and co-producing data and co-analyzing these with user(s) and/or recipient(s) to generate solutions that can be more applicable in real-world settings.

To enable better learning for readers, Chaps. 24, and 25 also provide a case study by Astell, Adlam, Hwang, and Williams and a learning activity by Sparrey. First, the case study introduces the NANA (Novel Assessment of Nutrition and Ageing) project which sets out to co-create a digital tool with older adults for daily home usage by highlighting an example of how partnering with the intended users of your research is key to producing accessible, practical products and services that people want to use. Second, the learning activity provides a structured brainstorming exercise and serves as a useful learning resource for facilitating the co-production of ideas and effective working across diverse teams.

After co-development of the study design and research instruments, the next step of the research process typically requires thinking about whether the research adheres to ethical standards. Chapter 26 by Sixsmith and Sixsmith provides an instructional overview of the research ethics process aligned with the key principles of bioethics:

- Non-maleficence (first do no harm, ensure as little harm to participants as possible)
- Beneficence (duty to ensure there is some benefit to the participant for their participation)
- Autonomy (right of participant to make informed and voluntary decisions)
- Justice (ensures fairness and that participants are treated equally)

As an extension of Chap. 26, Wang and Bickenbach discuss in Chap. 27 ethical considerations specific to health research, innovation development and implementation. Their argument is that ethics in research should not be an afterthought in innovation development because it is the responsibility of every person who is involved in the project, and that often, there exists important ethical considerations at all stages of the research and development process. Chapter 27, therefore, offers the following key ideas:

- "Everyone is an expert" in ethics.
- Ethics in health research is everyone's responsibility.
- Health research ethics involves three core principles (respect for persons, concern for individual well-being, and justice across the population).
- Developing ethics applications for review and approval takes understanding, familiarity, and practice.

Once ethical considerations are mapped out for all stages of the research and development process, turning research ideas into products is a good transitioning step toward developing innovations that can have real-world impact. Aligned with the ideas introduced by Astell and Fels, Jackson and Hwang in Chap. 28 emphasize that to ensure a successful research project, the idea should be co-designed, developed, and shared in such a way that it is accepted and used by the wider public. In their proceeding chapter, the authors provide some useful methods on stakeholder involvement. The co-design techniques and strategies introduced here include personas, scenarios, and use cases. Jackson and Hwang provide useful examples to demonstrate how personas, scenarios, and use cases can be widely used as tools for producing successful products. Additionally, how they are also be used as an effective method for developing and testing ideas which are formed as part of the user-centered design approach. A user-centered design approach that puts people first and is ideal for spanning boundaries of specialization.

As emphasized by Jackson and Hwang, it is important that we find effective ways to co-create and share knowledge to improve stakeholder involvement to ensure the end-product is appropriate for public consumption. Therefore, it is crucial to put appropriate measures in place and to make certain new innovations are suitable across the diversity of people with different cultural backgrounds. Chapter 29, by Mortenson, Auger, Johnson, and Guay, discusses important the cultural considerations researchers and innovators should take into account when developing technology solutions that transcends across cultures. These considerations include:

- Language
- Living and home culture
- Ethnic or religious influences
- Political and socioeconomic factors

Subsequently, to expand on ideas provided by Jackson and Hwang as well as Mortenson and colleagues, the next chapter by Southwick and colleagues describes their experiences when attempting to facilitate ongoing, interactive relations between 'makers and users' during prototyping. Key ideas outlined in Chap. 30 are:

- Determining what counts as participation when designing a real-world intervention.
- Identifying, considering, and learning from the underlying social context can support for the successful deployment of products, services, and interventions.
- Encouraging a culture of responsibility that extends throughout prolonged design and product maturation cycles.

Importantly, Southwick and colleagues highlight how often an ideal step for fostering multifaceted, long-term engagement among researchers, designers, and stakeholders occurs during prototyping. To do this effectively, their chapter is also accompanied by a case study and a learning activity. The case study provided by Ratto, Southwick, and Resche discusses the importance of taking time to validate technology products and presents an example of this for the validation of *3D PrintAbility*—a 3D scanning, design, and printing toolchain developed by Nia

Technologies. The case study is followed by an overview of *The Design Dash*, an activity also introduced by Resch, Southwick, and Ratto which enabling (in a practical way) collaborative teams to reflect critically upon the various impacts their solution might have on its target audience.

Finally, a step that is often missed in research, often due to the lack of time and resources, is evaluation. Park and colleagues begin their chapter by argueing how evaluation approaches in research, particularly in health technology, have largely been inadequate. To address this issue, their chapter presents an existing evaluation framework and illustrates how this can be applied in health research and specifically for developing health technology solutions. Park and colleagues discuss the implementation of this framework according to the following key ideas:

- Ranking quality of evidence for health technology solutions
- Classification of health technology solutions based on users
- Evaluation metrics for health technology solutions
- Evaluation approaches for health technology solutions

Chapter 33 is also accompanied by a case study that describes WelTel, a two-way SMS patient case management application. Park and colleagues' case study offers readers a practical example for including evaluation as an important additional step when conducting health research.

Outcomes and Impact

In recent years, researchers are increasingly using methods that facilitate the involvement and participation of multiple stakeholder groups, especially those who seek to benefit the from the research. Co-design and development methods have been adopted to varying degrees, but there is still much improvement to be made on how these can be implemented. The co-design experiences, methods, and strategies described in this section are dynamic and enriching. Additionally, they are practical for developing and implementing research that is co-produced with persons who are not traditionally involved in many aspects of the research process.

Key ideas provided in the chapters for this section help us to better understand the needs, aspirations, and everyday lives of those we aim to serve and can facilitate the development of practical solutions which can be transformed into real-world products and services. To help make certain this occurs, it is important that contingencies for identifying knowledge gaps, approaches for co-design, methods for co-production, effective and inclusive prototyping, and assessing effectiveness are built into research plans at the outset. Ensuring the real-world impact originating from research matters because spending public funds means that we are accountable for generating tangible societal benefits. To do this effectively, the key lessons introduced in this section can help our research be more efficient, of high quality and benefits those we aim to serve in the shortest time possible.

References

Canadian Institutes of Health Research. (2004). *Knowledge translation strategy 2004–2009: Innovation in action*. http://www.cihr-irsc.gc.ca/e/26574.html.

Grigorovich, A., Fang, M. L., Sixsmith, J., & Kontos, P. (2019). Defining and evaluating transdisciplinary research: Implications for in aging and technology. *Disability and Rehabilitation: Assistive Technology, 14*(6), 533–542. https://doi.org/10.1080/17483107.2018.1496361.

Maasen, S., & Lieven, O. (2006). Transdisciplinarity: A new mode of governing science? *Science and Public Policy, 33*(6), 399–410.

May, C., & Finch, T. (2009). Implementing, embedding, and integrating practices: An outline of Normalization Process Theory. *Sociology, 43*(3), 535–554.

Polk, M. (2015). Transdisciplinary co-production: Designing and testing a transdisciplinary research framework for societal problem solving. *Futures, 65*, 110–122.

Research Councils UK. (2014). *Pathways to impact*. https://www.ukri.org/innovation/excellence-with-impact/pathways-to-impact/.

Chapter 22
Reviewing the Literature

Steve MacGillivray

A literature review in any area is essential as it can offer a comprehensive overview of the current state of knowledge, including the provision of answers to specific questions but also, crucially, where the gaps in a particular evidence base may be.

The Challenge

Bodies of literature reporting the findings of research studies exist in most areas of academic enquiry. Contained within the literature are answers to specific questions posed by researchers, practitioners, and policy makers. Literature reviews are important for doing good research and are an essential part of the research process with almost all researchers having to conduct some form of review of the literature at some point. Anyone who is faced with conducting a review of the literature in any given field, however, will quickly become aware of the vast amounts of published and unpublished works that exist. Moreover, they will become aware that year on year, there is a substantial and ever-increasing addition of literature to that field. Such large bodies of literature often contain many articles that do not report study findings. Of those reports that do describe a study (e.g., qualitative study or quantitative study) and present the study's findings, the literature can vary considerably in the quality of its design, conduct, and reporting. Studies can also vary with regard to their findings. Furthermore it is often the case that there is much repetition and overlap of studies' purposes. Faced with such a mountain of varied literature, the seeker of answers is faced with problems in finding the literature to answer their specific questions and in determining what the best evidence available is and how

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this provides answers to the questions that they posed. There are many different ways to go about conducting reviews that can be challenging for the novice and which are not always done well even by those with some experience of doing them. Some examples can be found in Box 22.1.

Box 22.1 Different Types of Reviews

Narrative Reviews

They are informal, often unsystematic, and use subjective methods to collect and interpret information. This type of review is usually not considered methodologically rigorous. Details of the methods that relate to searching, data synthesis, and quality appraisal are not usually described. Findings are often summarized subjectively and narratively. Narrative reviews are more prone to bias and overestimate the value of some studies although they are quick to perform and are known to be performed by experts in the field.

Systematic Reviews

A review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant primary research and to extract and analyze data from the studies that are included in the review. Systematic reviews are highly rigorous forms of reviews that aim to minimize bias; are replicable, useful for resolving controversy between conflicting findings; and can provide for a reliable basis for decision-making. However, systematic reviews are both time and resource intensive.

Scoping Reviews

Systematically assess the breadth of a body of literature in a particular research area. They are used to map key underlying concepts of the area in question and may, therefore, help to identify research gaps in existing literature. Scoping reviews differ to that of systematic reviews in that they are exploratory in nature while still aiming to maintain the same level of rigor.

Realist Reviews

The focus is on understanding and unpacking the mechanisms by which an intervention works (or fails to work), thereby providing an explanation, as opposed to a judgment, about how it works. The realist approach is fundamentally concerned with theory development and refinement, accounting for context as well as outcomes in the process of systematically and transparently synthesizing relevant purposefully selected literature.

Environmental Scans

Is a needs assessment tool that can be utilized to inform program development tailored to the needs of the communities. Environmental scans can be used for strategic planning, organizational development, information management, and enhancing an organization's ability to anticipate and respond to changes in the environment. They are also used as a planning tool to strengthen public health information and technology resources, to guide regional healthcare reform, and to assist in planning and development.

The process of the different types of reviews largely stems from the systematic review. This chapter provides an overview of the key ideas and concepts of the systematic review. The systematic assembly, appraisal, and synthesis of the findings from multiple individual studies are employed and valued across a wide range of fields. The key ideas that will be addressed here are the following:

- Value of involving *users* in preparing and conducting a literature review.
- Importance of understanding how to plan a literature review and the key steps that are involved.
- Need for clear and transparent methods to be used to search for and appraise the literature.

Key Ideas

The Value of Involving Users in Preparing and Conducting a Literature Review

Users of any research findings (stakeholders) vary and may include people who receive a service, intervention, or program; people who deliver a service, intervention, or program; policy makers who develop policy to guide the commissioning and uptake of services, interventions, or programs; researchers; and funders of research activity. If the involvement of stakeholders in the systematic review process is to be more than tokenistic, the process should involve their input throughout, from inception to completion of the review and beyond. A good way of ensuring meaningful user input throughout is to appoint an advisory group at the earliest opportunity, preferably before the review has commenced. It is not always the case, however, that a fixed membership group is required; rather the involvement of different users at different steps of the review process may be preferable and beneficial.

The Importance of Understanding How to Plan a Literature Review and the Key Steps That Are Involved

Planning and conducting a rigorous and robust review of the literature is not easy, and like many other research methods, it requires careful and detailed planning (Hemingway & Brereton, 2009). There are three main steps involved in planning and conducting a review: determining the need for the review; developing a protocol; and implementing the protocol.

Determining the Need for a Review and Developing the Review Questions

Like any research study, reviews begin with an argument that builds toward the reason for the review. This nearly always involves an awareness of relevant existing literature. Indeed, it is often an awareness of the existence of equivocal research findings that is the prompt to go on to conduct a review of all relevant literature. One hope may be that in conducting a review, a definitive answer may be found.

In any research study, well-crafted questions guide the systematic planning and implementation of the research method. Indeed, the research questions should *beg* the method that is to be used to answer them. This is very true for conducting literature reviews, where formulating the questions precisely enables the design of a review with a good chance of answering them. This is particularly important when you are faced with a mountain of literature, where imprecise questions may leave you floundering as you try to decide whether studies should be included and what you may or may not need to consider regarding the data they present. Precise questions should give you a clear sense of *exactly* what a study should be to be included or excluded. Precise questions also allow you to focus *only* on the relevant findings that particular studies may provide to answer those questions. For this reason, when deciding upon your review questions, it is worth spending considerable effort and time in formulating, constructing, and writing the precise questions that you wish to answer. Working with others, including potential users of the review, to do this is very beneficial as it allows a discussion to take place such that ideas are shared, questioned, scrutinized, debated, and refined. Drawing upon existing literature can also help with this process, particularly in considering exactly which questions have already been asked and which still need to be answered (see Box 22.3).

Developing a Review Plan (Protocol)

The protocol includes two important components: planning the eligibility criteria for the review (i.e., which studies will be included and excluded) and planning the methods that will be used throughout the review process (see Box 22.2). The protocol should detail the methods to be used in order to search for and screen the literature as well as those that will be used to appraise the quality of included studies and to extract and analyze any data (qualitative and/or quantitative).

Box 22.2 The Key Steps of a Literature Review

1. Identify the need for the review and ensure that it has not already been performed (involving potential users and/or key stakeholders as early as possible in the review process).
2. Design a protocol that details the questions to be answered and the methods that will be employed.
3. Implement the protocol by:
   - Searching for the literature.
   - Screening the literature with regard to clearly formulated inclusion criteria. Many studies can subsequently be excluded at this step.
   - Appraising the quality of the literature.
   - Extracting the relevant information/data from the included literature.
   - Describing the range and nature of the literature.
   - Performing some form of synthesis/analysis/reporting of the literature such that it answers the initial review questions posed.

Box 22.3 Tip for Researchers

When planning a literature review, begin by searching for any existing reviews in your area of interest. Such reviews can help you to determine what has already been reviewed but also may provide you with an understanding of how to go about planning and conducting your review. You may, for example, be able to adapt an existing search strategy for your review.

Implementing the Protocol (Conducting the Review)

Once you have planned and co-designed your protocol, it is merely a case of implementing it. If the protocol has been well planned, then all of the thinking and planning that went into the development of the protocol should, in theory, require the reviewer(s) to follow it is as though following a recipe. However, as with all research, problems, issues, and dilemmas may occur. The researcher may discover that their inclusion criteria were too strict (or too loose) or perhaps that the methods they proposed to analyze or report the data were inadequate.

The Need for Clear and Transparent Methods to Be Used to Search for and Appraise the Literature

The search strategy is a vital part of the review protocol because it stipulates where you will be searching for studies (i.e., electronic databases, websites), the terms you will use to search for studies, and also details any limitations you might want to put on your search (e.g., date, language). Search strategies help minimize bias in your review by identifying as many relevant studies as feasibly possible and thus avoids the reviewer merely selecting studies. Moreover, a search strategy should enable your search to be replicated by others, which is a major factor in what makes reviews *systematic* (Lefebvre, Manheimer, & Glanville, 2011). In order to be effective, a search strategy needs to be able to identify all of the studies relevant to the review question. Often, this means that as well as finding all relevant studies, the search may also find many studies that are not relevant to the question. The best search will return all possible studies, but in order to ensure this, it is usually necessary to include many studies that are not relevant. If you have clearly defined the inclusion and exclusion criteria, it should not take long to exclude many studies simply by examining the title and abstract of each study. An experienced reviewer, with clearly framed inclusion and/or exclusion criteria, may take 1 day to screen 1 or 2000 titles and/or abstracts, for example.

Once you have identified the literature to be included in your review, it is important to appraise the literature. Critically appraising the literature is a fundamental step in the review process. Once all of the studies to be included in a review have been retrieved, it is important to assess them in order to identify any strengths and weaknesses they may possess. This process involves evaluating how trustworthy studies are and how reliable as well as how credible and valuable they are. The process is usually described as assessment of study quality. Beware of this term, however, as *quality* can be used to refer to reporting quality and study quality. These are distinct concepts that are often confused. This confusion persists because some of the available tools that reviewers can use to assess study quality often contain a mixture of these two things.

Reporting Quality

How well a particular study has been reported is known as the reporting quality. This is important because if a study was poorly reported with regard to the study's objectives, methods, results, and implications, the reviewer may not be able to determine how well the study had been conducted or to identify relevant results. It should be noted that while there is often a relationship between reporting quality and how well a study has been conducted, one does not necessarily follow the other. A poorly reported study may have actually been a study that was extremely well conducted and vice versa. Fortunately journals have improved greatly in recent times with regard to the quality of reporting. This improvement has been driven by the work of the EQUATOR (Enhancing the QUAlity and Transparency Of health Research) Network, which is an international initiative that aims to improve the reliability and value of published health research literature by promoting transparent and accurate reporting and a wider use of robust reporting guidelines (http://www.equator-network.org/). EQUATOR has developed and prepared several types of guidelines for the reporting of a variety of study types (see Box 22.4).

Box 22.4 Reporting Guidelines for Different Study Types

Study type	Reporting guideline
Randomized trials	CONSORT
Observational studies	STROBE
Systematic reviews	PRISMA
Case reports	CARE
Qualitative research	SRQR or COREQ
Diagnostic/prognostic studies	STARD or TRIPOD
Quality improvement studies	SQUIRE
Economic evaluations	CHEERS
Study/review protocols	SPIRIT or PRISMA-P
Clinical practice guidelines	AGREE or RIGHT

Poor reporting can hinder assessment of study quality; however, a well-reported study is not necessarily of a higher quality or free from bias.

Study Quality

The concept of study *quality* is not well-defined but relates to the extent to which the study's design, conduct, analysis, and presentation are appropriate to answer the research questions (Higgins et al., 2016). This is to say that it is the extent to which the study has been performed to the highest possible standard.

Numerous tools are available in order to guide assessment of study quality. Many of these provide a summary measure, but they are not supported by empirical evidence. Such an approach can provide unreliable assessments of validity since a study can fall down on only one important element of study design but still receive a fairly high overall measure. It is often difficult to justify weights attributed to particular items or components of a checklist.

In Box 22.5 there are samples of generic questions you may ask of the literature in order to determine reporting quality and study quality. It should be noted that questions will vary and are dependent upon the exact type of study: qualitative studies will differ greatly from quantitative studies in regard to what constitutes a good study. The researcher should aim to ask questions about study quality with regard to specific components of the study type(s) they are including in their review.

Box 22.5 Quality Questions
Reporting Quality Questions

- Is there a clear description of the study purpose and research questions?
- Are the methods that were employed clearly described?
- Is there a clear description of the study participants?
- Are the results clearly described, and is there any missing data?
- Is the study adequately reported to allow assessment of study quality?

Study Quality Questions

- Were methods used to identify and include study participants appropriate?
- Are the study's participants representative of the population they are drawn from?
- Are the study's findings generalizable or transferable?
- Were methods used to collect data appropriate?
- Were methods of data analysis appropriate?

Product Innovation Pathway Model

The methods and purposes of different literature reviews will vary, and the process of planning and conducting a review is often iterative. Thus some of the activities listed below may happen throughout all steps, and researchers may need to go through multiple cycles of the PIP model. However, the key steps of a literature review are aligned with this model (Table 22.1).

Learning More
Talk to your research colleagues that have experience in conducting reviews of the literature. Your organization or home institution may also have someone who is specifically skilled in this area. Visit the websites of key organizations in your area that may commission, prepare, or conduct literature reviews. The following are some key resources for further reading (Arksey and O'Malley, 2005; Aveyard, 2014; Boland et al, 2013; Gough et al, 2012).

- Petticrew, M., & Roberts, H. (2008). *Systematic reviews in the social sciences: a practical guide*. Oxford: Blackwell. Provides an overview of all steps in the systematic review process. This book is written by social scientists and is particularly useful for those doing reviews of complex interventions.
- Rowel, R., Moore, N. D., Nowrojee, S., Memiah, P., & Bronner, Y. (2005). The utility of the environmental scan for public health practice: lessons from an urban program to increase cancer screening. *Journal of the National Medical Association, 97*(4), 527–534.
- Rycroft-Malone, J., McCormack, B., Hutchinson, A. M., DeCorby, K., Bucknall, T. K., Kent, B., … Wallin, L. (2012). Realist synthesis: illustrating the method for implementation research. *Implementation Science, 7*(1), Article no. 33.

Table 22.1 Product innovation pathway (PIP) model—reviewing the literature

PIP level	PIP description	Key activities
1	The need for a review	Know the literature in the area—particularly with regard to uncertainties; work with others (funders, policy makers, researchers, potential users of review findings) to identify the need
2	Planning	Determine resources that are available including personnel and timelines; identify potential funding to support activity
3	Development	Consult stakeholders and involve in the development of the review purpose and protocol; involve representatives of the public, organizations, and policy makers that are affected by the issues and/or will use the results; develop a review protocol and agree on timelines
4	Testing in real-world environment	Pilot the protocol and engage stakeholder involvement throughout the conduct of the review; refine the protocol if necessary; seek feedback from broader stakeholder group
5	Outcomes and impact	Make recommendations for practice and policy change; work with policy makers to legislate policy and with researchers to plan further research and users to assess the implications of the review findings; work with broader stakeholders to disseminate findings and determine future need

Key Messages

Conducting a robust and rigorous review of the existing literature is not easy and requires careful planning and execution. The engaged researcher needs to understand the methods that can be adopted in planning and conducting a review. They need to adopt an approach which includes:

- Determining the need for the review and to co-design a prior protocol with key stakeholders.
- Implementing the protocol in a transparent, reproducible, and rigorous manner.
- Providing connection to other key interest groups and the public related to a specific policy issue as well as latest published evidence and expert opinion.

References

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19–32.

Aveyard, H. (2014). *Doing a literature review in health and social care* (3rd ed.). Maidenhead: McGraw-Hill Education.

Boland, A., Cherry, M. G., & Dickson, R. (Eds.). (2013). *Doing a systematic review: A student's guide*. Thousand Oaks: SAGE.

Gough, D., Oliver, S., & Thomas, J. (Eds.). (2012). *An introduction to systematic reviews*. Thousand Oaks: SAGE.

Hemingway, P., & Brereton, N. (2009). *What is a systematic review?* (2nd ed., pp. 1–8). London: Hayward Medical Communications.

Higgins, J. P. T., Sterne, J. A. C., Savović, J., Page, M. J., Hróbjartsson, A., Boutron, I., … Eldridge, S. (2016). A revised tool for assessing risk of bias in randomized trials. In J. Chandler, J. McKenzie, I. Boutron, & V. Welch (Eds.), *Cochrane database of systematic reviews* (Vol. 10(Suppl 1), pp. 29–31). London: John Wiley & Sons. https://www.cochranelibrary.com/documents/20182/64256496/Cochrane+Methods+2016/9cd61dd1-04c1-338c-2279-7aa30953451f.

Lefebvre, C., Manheimer, E., & Glanville, J. (2011). Chapter 6: Searching for studies. In J. P. T. Higgins & S. Green (Eds.), *Cochrane handbook for systematic reviews of interventions, version 5.1.0*. London: The Cochrane Collaboration. (updated March 2011).

Chapter 23
Co-production Methods in Health Research

Arlene J. Astell and Deborah I. Fels

The Challenge

Successful health innovation requires more than the creation of a new treatment, service, or technology. It also involves gaining an understanding of the needs of the intended recipients or users of the innovation and the environment in which the innovation is going to be introduced. Innovating with the intended users or recipients of new health products is crucial for maximizing the chances of adoption and uptake of new ideas and technologies. Such co-production requires careful planning and facilitation to ensure productive partnerships and involvement of all parties affected by the health innovation. This chapter contains key ideas to help researchers co-produce health innovations with intended recipients or users of new products or services:

- Prerequisites for co-production.
- Determining appropriate user-centered methods.
- Collecting and analyzing the data.
- Integrating results into design.

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Key Ideas

Prerequisites for Co-production

Co-production takes a holistic approach, addressing the needs of the individual as well as the context into which an innovation is going to be introduced. This contrasts with traditional approaches that typically isolate variables of interest and seek to minimize interference from other areas. Specifically, successful co-production requires attention to identifying your co-producers, recognizing the co-producers' expertise, and providing an inclusive environment where everyone's voice can be heard. Various methods can be used to identify the co-producers for each product. One approach is to ask the question "Who will be affected?" and generate a list broken down by groups (e.g., patients and/or service users, their social circle, the staff directly affected, etc.). Another approach is to spend time in the environment that the innovation is targeting. Not only does exploring the environment permit identification of the co-producers, it also provides insight into how the environment functions and key aspects of current practice, which can inform how the new innovation could fit in.

Co-production recognizes that lived experience is as important in health innovation as scientific, medical, or research expertise. Any innovation will only succeed if it is adopted and used. User expertise can illuminate why people do or do not use things as intended (e.g., take their medications as prescribed, carry out recommended activities such as physiotherapy exercises and dietary changes, or use provided devices such as mobility or visual aids). Frontline staff is also expert in understanding challenges to innovation on the ground. For example, a technology that provides video consultations may be rejected by a lonely individual because that individual values the weekly visits from a staff member. Frontline staff can also highlight gaps in their services as well as demands on their services which might make adopting new innovations difficult, e.g., reliable Internet and time for training (Box 23.1).

Box 23.1 Information Users as Experts

A hospital specializing in the treatment and care of older adults offers a memory program to people concerned about their memory. This in-person program provides practice in memory strategies while addressing concerns about memory changes in later life and education about brain-healthy lifestyle choices. However, participation is limited to those who can travel to the hospital. To reach a broader audience, an online version is proposed. Using an iterative co-production process, a team of clinicians, researchers, e-learning experts, and developers work together with older adults to develop and refine the program. Older adults who had completed the program within the previous 12 months co-produce the program interface and the way in which the information in the modules is presented.

A second group of older adults who are new to the program work their way through the online version in their own homes, recording information about

(continued)

Box 23.1 (continued)
all aspects of its usability, accessibility, and enjoyment. The final product consists of interactive learning modules, animations, games, homework assignments, and real-time chats with co-learners that users find easy to use, appealing, and relevant. In terms of replicating the benefits of the original in-person program, the online version is so far producing high levels of user knowledge gain, behavior change, satisfaction, and personal goal attainment.

Successful co-production also requires an inclusive environment where everyone feels able to speak and everyone's contributions are valued. This is particularly important with co-producers who are unfamiliar with research or innovation or who are unfamiliar with giving their opinions in public forums. For example, patient co-producers may feel unsure about what they have to contribute, especially if the innovation relates to technology. Similarly, frontline staff who work directly with patients or service users are rarely asked for their ideas or their suggestions in relation to the services they work in or the people they care for or support. A code of conduct establishing ground rules for communication and interaction, e.g., respecting other people and their opinions and keeping sensitive or personal information confidential, such as personal experiences of patients or staff, can facilitate this (Box 23.2).

Box 23.2 Inclusive Environment
A local government provider of social care wants to redesign its assistive technology (AT) service to increase uptake of the devices it has available. The government provider works with one of the authors to create a daylong interactive workshop to bring together all parties with an interest in AT. This includes people who could benefit from aids for mobility, hearing, vision, and cognition, along with staff in hospital and community settings, housing, and other organizations supporting people using ATs. The workshop is structured and facilitated to ensure that the expertise of all of the participants is heard and is valued. Activities involve looking at factors that influence technology adoption, testing some technologies, and designing an ideal AT service for the local area. The outcome is a set of priorities for the service redesign for the social care provider to use, plus a group of experts to work with in developing it.

The priorities that emerge are (1) the importance of a central hub to support people and signpost additional services; (2) the service that should be for anyone who wants to maintain independence and improve quality of life rather than a medical service just for when people have specific physical needs; and (3) the service and available technologies that should be advertised through a wide variety of media and in a variety of community settings. The group also identifies how it wants to access and adopt assisted living technologies including support from appropriately trained staff, opportunities to use trial technologies in homes, and different payment models including rental and subscriptions.

Determining Appropriate User-Centered Assessment Method(s)

Determining what people want or need is a common first task in co-production. Many different needs elicitation and user-centered assessment methods have been developed by psychologists, sociologists, user experience experts, interface developers, computer scientists, human factors experts, and others. A recent review identified 18 different methods for needs elicitation. These include cultural probes, think-aloud protocol, technology interaction, and paper prototyping.

Similarly, a wide range of qualitative and quantitative methods are available for user evaluations, which are frequently combined in mixed methods studies. Conventional examples for collecting qualitative data include surveys, interviews, card sorting techniques, and observational and think-aloud methods. Methods for collecting quantitative data involve metrics and validated measures such as self-report and observational measures, visual acuity measurement, and cognitive assessment metrics. However, not all methods are equally well suited for all evaluation purposes or for all potential audiences, particularly older adults or people with disabilities. In addition, it is not always obvious which methods would be optimal for a specific stakeholder group. Across all fields, innovators tend to favor methods they learned during training or have used before without necessarily considering whether the method is a good fit for their particular evaluation strategy. Sometimes existing methods can be modified, but in other cases, individuals may be excluded because they cannot participate in a particular methodology. In some situations, user-centered assessment may be avoided altogether because it is perceived as too difficult or time-consuming. On the positive side, newer methods such as participatory design, idea jams, and design jams are being developed and introduced to tackle these limitations and extend user participation in co-production.

This raises the question: How can a developer or designer know which method to choose and how it best fits with their target users? Most user-centered method descriptions do not provide a guide to what users are required to be able to do to participate in them, nor ways to assess the fit of the method with either the evaluation strategy or user characteristics. Using the four main human capability categories: vision, hearing, cognition and mobility, Roy, Neumann, and Fels (2017) have developed NICKEL, a needs elicitation methods selection tool to assist designers in determining appropriate methods using four main human capability categories: vision, hearing, cognition, and mobility. Designers estimate the capabilities that they think their potential users will have and then enter them in NICKEL and receive a recommendation for possible methods (http://tungsten-training.com). For example, hearing capabilities can be *hearing*, *hard of hearing*, or *deaf* (see example in Box 23.3). While this is only one way of assessing appropriate methods, it asks designers to consider who their co-producers will be and what abilities their co-producers possess. It also challenges the notion that all methods can work with everyone.

Box 23.3 Determining the Appropriate User-Centered Assessment Method(s)

A designer wants to include deaf users who speak a signed language in a usability evaluation for a new Web application. However, typical usability methods such as think-aloud protocol and answering questions on a questionnaire are not conducive to sign language. Think-aloud protocol requires that a user work through a set of typical tasks with a technology and talk about what they are thinking in real time. Signed language users talk with their hands, face, and body; thus, they cannot use a computer interface (e.g., typing or using a touch pad or mouse) while talking. Online questionnaire tools do not allow for video-based questions instead of text. Signed language users often have weak text-based skills and cannot fully understand or express themselves with text. This dilemma requires a new method that allows signed language users to test the Web application and provide feedback in real time. The gestural think-aloud protocol (Roberts & Fels, 2006) was developed and disseminated for this purpose. Deaf users can work with an interface and sign in real time. A signed language interpreter can simultaneously provide live interpretation for hearing developers or designers.

Analyzing Co-production Data

Gathering and analyzing co-production data generally employs a mixed methods approach, using both quantitative and qualitative data collection and analysis methods. Quantitative analysis methods usually refer to statistical procedures, while qualitative methods involve finding patterns, commonalities, or anomalies in verbal, visual, or text data provided by people.

Quantitative data. It is often difficult to recruit sufficient numbers of participants who fit specific selection criteria. This means that relatively small numbers of individuals (small *n*) are often involved in co-production, and the sample does not meet the assumptions of parametric or regression statistical analyses. However, there are multiple statistical and qualitative analysis methods dedicated to small *n* designs, e.g., Norman (2010). For example, a case study methodology can be used (Meyer, 2001), where one or a specific group of people (series of case studies) is studied and reported on in-depth. Nonparametric statistics such as the Mann-Whitney *U* test or the Kruskal-Wallis test are suitable when non-normal distributions and/or small sample sizes are used. There is considerable research on the use and procedures for nonparametric statistics going back to Siegel (1957). Another common quantitative approach for small sampled studies is repeated measures or *within-participants* design wherein each participant carries out multiple tasks or parts of a study. With repeated measures there can be a learning effect or influence from completing multiple parts of the same study; thus the statistical analyses must account for this possibility. Repeated measures ANOVA or the nonparametric Friedman's test is commonly used to analyze data collected from within-participants studies. When there are a sufficient number of participants, the statistics can be more complicated but also more powerful in generalizing the results to a larger population. Parametric tests of difference, such as Student's *t*-test and analysis of variance (ANOVA), factor analysis and regression statistics, and multivariate statistics such as structured equation modelling, are common approaches.

Evaluating the usability and utility of products is a common purpose of product innovation assessment that can occur at different steps of the design process. Usability testing is utilized to identify problems or issues with a product or tool from a user's perspective in the areas of learnability, usefulness, efficiency, effectiveness, satisfaction, accessibility, and ease of use (Bevan, Carter, & Harker, 2015). Utility testing is used to determine the effectiveness of the functionality with users (Rogers, Sharp, & Preece, 2011). As the main purpose of these types of evaluation is to identify problems, statistical significance is not that useful. It has been proposed that having between 3 and 16 evaluators (users) is sufficient to identify 90% of usability problems (Molich & Nielsen, 1990). To find the remaining 10% requires many more evaluators. Graphical techniques and frequency diagrams provide ways of visualizing how many participants found any one problem and/or issue (or set of related problems) and can assist in assigning priority to those problems and the ordering of resolutions to those problems. However, it is important not to dismiss usability issues or problems or ideas identified or contributed by a single user and/or evaluator, as they can unearth more obscure but critical functionality or design ideas.

Qualitative. There are numerous approaches for analyzing qualitative data, but selecting the best method can be confusing. It is important to keep in mind the purpose of collecting the qualitative data and what is needed from it. If the purpose is to find meaning or to generate a theory about a specific problem or set of problems, then grounded theory can be useful (Glaser, 2017). If the purpose is to identify or confirm a common set of themes among what people have said or written during a study, then methods such as thematic or content analysis are helpful (Miles, Huberman, & Saldaña, 2014). If the interest is in finding how often specific words or phrases appear in written, spoken, or signed works and/or how often specific words or phrases appear close together, discourse analysis may be the best approach (Gee, 2014). Useful software includes NVivo and QDA Miner for textual analysis and Noldus Observer™ for video analysis.

This very brief description demonstrates the many possible methods available to analyze co-production data, and there is no right or wrong way. Definitive statements about general patterns of most of the population necessitate large quantities of data and fairly sophisticated statistical analyses. However, problem or issue identification requires less data. Mixed methods allow the richness and messiness of human commentary, opinions, behavior, and thoughts to complement more objective and focused, but limited in scope, sets of numbers. This can then help to answer questions not only about *What?* but also *Why?*.

Integrating Results into Design

The tenets of user-centered design hold that user needs and user data must be incorporated into product designs or revisions from the very beginning of product innovation. Planning for the time and resources required for ongoing user testing is essential and necessary at the specification step, to avoid expensive retrofits or product acceptance failure due to usability issues. However, product developers, management, and marketers do not necessarily accept or understand the relationship between having users involved early in the design process and the final product's use, performance, and adoption. User evaluation can increase the time to market and/or cost of developing a specific product. In addition, the product development team may have little or no experience in capturing and integrating user-based information into products. This highlights the importance of building capacity in the team, e.g., iterative prototyping, working with users, and mixed methods. An archive of all data including audio and video recordings, sketches, made objects, or photographs should be maintained to assist designers and developers in understanding user feedback and input in context.

Product Innovation Pathway Model

Co-production is essentially a mind-set for innovation. The approaches introduced in this chapter are intended to assist in thinking about how to work with users of products and services to co-create products and services that will fit into their lives (Table 23.1).

Table 23.1 Product innovation pathway (PIP) model—co-production methods

PIP level	PIP description	Key activities
1	Innovative ideas	In co-production, innovative ideas can come from anyone. Bring together researchers, developers, and people with direct experience of an issue to identify problems, opportunities, and potential solutions in workshops, knowledge cafés, and informal interviews. Take time to do a scan and jointly evaluate ideas and solutions from elsewhere, e.g., other application areas or countries
2	Planning	Forward plan your co-production activities. Think about the types of interactions and activities you will engage in, the purpose of these interactions and activities, their duration and frequency, the types of data to be collected, and how these will be analyzed
3	Development	Co-production develops as ideas are fleshed out, prototyped, and iteratively tested. This can be achieved with one dedicated group of users or testing each version with new users to see how they respond *cold* to the latest changes. Video recording is a great tool for capturing user reactions and exploration
4	Testing in real-world environment	Conduct co-creation into the context in which an innovation is going to be used. This can be a person's home, workplace, school, sports venue, transport, etc. real-world testing takes out all the potential obstacles to an innovation being successfully deployed
5	Outcomes and impact	Start by identifying: What does success look like? In the memory program described in Box 23.1, success is a fully interactive Web-based program that offers the same benefits to users as the face-to-face original. This will enable you to plan out a series of co-production activities to get you to where you want to be

Learning More

To find out more about the co-production methods mentioned in this chapter, please access the TUNGSTEN website (http://tungsten-training.com/). For further information about using the co-production methods, please contact the authors.

Key Messages

- Co-production starts with the intended users or recipients to ensure innovations are adopted, not rejected nor abandoned.
- Users and/or recipients are experts about their situation and are equal in the process.
- Create an environment where everyone's voice can be heard.
- Think carefully about what you want to gain from co-production.
- Review different co-production methods to identify the right one(s) for your purpose.
- Don't be afraid to try new approaches.
- Co-production data and analysis can be useful in demonstrating the technique and justifying design.

References

Bevan, N., Carter, J., & Harker, S. (2015). ISO 9241-11 revised: What have we learnt about usability since 1998? In M. Kurosu (Ed.), *International conference on human-computer interaction* (pp. 143–151). Cham: Springer. http://link.springer.com/chapter/10.1007/978-3-319-20901-2_13.

Gee, J. P. (2014). *An introduction to discourse analysis: Theory and method*. New York: Routledge.

Glaser, B. (2017). *Discovery of grounded theory: Strategies for qualitative research*. New York: Routledge.

Meyer, C. B. (2001). A case in case study methodology. *Field Methods, 13*(4), 329–352.

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks: SAGE.

Molich, R., & Nielsen, J. (1990). Improving a human-computer dialogue. *Communications of the ACM, 33*(3), 338–348.

Norman, G. (2010). Likert scales, levels of measurement and the "laws" of statistics. *Advances in Health Sciences Education, 15*(5), 625–632.

Roberts, V., & Fels, D. (2006). Methods for inclusion: Employing think aloud protocols in software usability studies with individuals who are deaf. *International Journal of Human-Computer Studies, 64*(6), 489–501.

Rogers, Y., Sharp, H., & Preece, J. (2011). *Interaction design: Beyond human-computer interaction* (3rd ed.). New York: John Wiley & Sons.

Roy, J. S. S., Neumann, W. P., & Fels, D. I. (2017). Human capability demands required from the elderly and disabled participants in the user centred design needs elicitation methods—A survey study. In *Proceedings of the 48th annual conference of the Association of Canadian Ergonomists* (pp. 496–502). Banff, Alberta, Canada. https://ace-ergocanada.ca/files/ACE_2017/ACE-ODAM%202017%20eProceedings_sm.pdf.

Siegel, S. (1957). Nonparametric statistics. *American Statistician, 11*(3), 13–19.

Chapter 24
Case Study: Co-creating NANA (Novel Assessment of Nutrition and Ageing) with Older Adults Living at Home

Arlene J. Astell, Tim Adlam, Faustina Hwang, and Liz Williams

The Challenge

Older people face a high risk of nutrient deficiencies and malnutrition, which increases risk of sarcopenia (loss of muscle mass and strength) and other health-related problems. Avoiding late-life malnutrition is dependent on a number of factors including physical, mental, and cognitive health. Monitoring all of these factors and the interactions between them is challenging, especially for people living at home. Dietary intake, for example, has traditionally used pen and paper recall and recording of what people eat (e.g., food log, food diary), which relies heavily on memory. In addition, gold standard measures of cognition are designed for one-off assessment, administered by a trained clinician or researcher. Developing an accessible tool that older people can use at home on a daily basis to monitor what

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they eat and drink, their mood, cognition, and physical activity could reassure them how they are doing and provide early detection of emerging problems.

The NANA (Novel Assessment of Nutrition and Ageing) project set out to co-create a digital tool with older adults that they could use at home on a daily basis. A team of nutritionists, psychologists, engineers, and human-computer interface experts developed a comprehensive program to facilitate cooperation between the relevant stakeholders and ensure maximum input at every stage. This comprised three key elements: (1) *Whole project management*, where every part of the project is seen in its relation to the whole, i.e., part of delivering the NANA tool kit—rather than in disciplinary or work package silos; (2) *Transdisciplinary working*, where team members from different disciplines work together, across boundaries, for example, an engineer and nutritionist running a technology focus group; and (3) *Partnership with older adults*, whereby older adults iteratively co-create the different aspects of the project (Astell et al., 2018).

This partnership approach influenced the project design and resulted in us carrying out a total of 44 sub-studies ranging from working with two individuals in their own homes to examine the usability of a video camera for recording their daily food and drink to the full NANA tool kit evaluation in 40 individuals' homes (Astell et al., 2014). These 44 sub-studies were organized in three phases:

Phase 1 User needs analysis

The first phase comprised 12 sub-studies: seven focus groups—three with older adults, two with nutrition professionals, and two with other health professionals—plus five field studies with older adults: (1) evaluating currently available smart phones on the high street, (2) feasibility of older adults recording their food and drink using digital photography, (3) video camera, (4) early mock-ups of the NANA interface, and (5) acceptability of and preferences for different sized touch screens in the home.

Phase 2 Development of Integrated Measurement Tool Kit

This phase comprised 26 sub-studies informed by the findings from Phase 1 across three integrated strands: (1) iterative design and development of the measurement tool kit, (2) dietary validation studies, and (3) cognition and mental health validation studies. In brief, these sub-studies were: food recording (Brown et al., 2018), food weighing (Timon et al., 2015), portion size estimation (Astell et al., 2018), activity monitoring (Astell et al., 2014), gait (Brown et al., 2016), cognition and gait (Astell et al., 2018), cognition and mood (Astell et al., 2018), grip strength (Timon et al., 2015), tool kit configuration (Brown et al., 2016), and two validation studies: nutrition (Astell et al., 2018) and diet, mood, and cognition (Astell et al., 2018).

Phase 3 Full Tool Kit Validation

The third phase of the project included four sub-studies including the main validation study comparing the NANA tool kit with the best pen and paper methodologies and against independent biochemical markers of nutrient status. Three other sub-studies are: comparison of methods of collecting gait data in the home setting, potential for steadying the older adult's gait, and a final focus group with older adults and health care staff to discuss the potential application of the data collected by the NANA system. The NANA project directly involved 533 older adults (aged between 65 and 91 years) plus dietary information from another 217, along with 53 nutritionists as well as 15 health professionals and 90 adults under 65 years of age.

Outcomes and Impact

The major outcome was the validated NANA tool kit that older adults can use at home to keep track of their food and drink, cognition, mood, and physical activity (Astell et al., 2014). This comprises a new digital method for capturing accurate dietary information (Timon et al., 2015); novel, reliable, repeatable cognitive measures (Brown et al., 2016), which are used along with new daily mood measures (Brown et al. 2018), which can predict future depression (Andrews et al., 2017). Through the COBALT (Innovate UK, 2011–2013) and TUNGSTEN (AGE-WELL) (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life)

Network of Centres of Excellence, 2015–2020 projects we have translated the NANA transdisciplinary approach into co-created activities for technology developers to partner with older adults as experts (http://tungsten-training.com/). A mobile version of the NANA nutrition module was co-created with younger adults with intellectual disability in the CANDI project (Sirona Foundation 2015–2016). The complete NANA tool kit has been co-developed into DataDay, a mobile self-management application for people living with dementia with funding from AGE-WELL and CABHI (2017–2019). DataDay is currently in beta testing with a view to commercialization in 2019.

Key Messages

- Older adults are experts in their needs, preferences, and priorities.
- Partnering with older adults is key to producing accessible, practical products, and services that people want to use.
- Daily monitoring can provide reassurance and early detection of problems.

Project Details and Team This work was supported by grant #ES/G008779/1 from the New Dynamics of Ageing program, administered by the United Kingdom's Economic and Social Research Council. The project ran from April 2009 to June 2013 with a grant of £1,035,060 GBP (100% FEC; includes two Ph.D. studentships). Dr. Arlene Astell (University of St. Andrews [Scotland]) was Principal

Investigator with Co-investigators Dr. Tim Adlam (Designability and University of Bath [United Kingdom]), Dr. Faustina Hwang (University of Reading [United Kingdom]), and Dr. Liz Williams (University of Sheffield [United Kingdom]). Dr. Laura Brown (St. Andrews), Dr. Alan Godfrey (Reading), and Dr. Sarah Cooper (Sheffield) were the NANA postdoctoral researchers. Hassane Khadra was the NANA engineer (Designability) and Tom Smith (Reading) was the NANA programmer. Dr. Lin Maclean (St. Andrews) and Dr. Claire Timon (Sheffield) were the NANA Ph.D. students. Sanctuary Care Ltd. and Age UK were partners in the project, with Age UK hosting the NANA Advisory Group, chaired by Professor Peter Lansley (Reading).

References

Andrews, J., Harrison, R., Brown, L. J. E., MacLean, L. M., Hwang, F., Smith, T., … Astell, A. J. (2017). Using the NANA tool kit at home to predict older adults' future depression. *Journal of Affective Disorders, 213*, 187–190.

Astell, A. J., Hwang, F., Brown, L. J. E., Timon, C., Maclean, L. M., Smith, T., … Williams, E. A. (2014). Validation of the NANA (Novel Assessment of Nutrition and Ageing) touch screen system for use at home by older adults. *Experimental Gerontology, 60*, 100–107.

Astell, A. J., Williams, E. A., Hwang, F., Brown, L., Cooper, S., Timon, C., … Godfrey, A. (2018). NANA: A tale of ageing and technology. In A. Walker (Ed.), *The new dynamics of ageing* (Vol. 2, pp. 157–176). Bristol: Policy Press.

Brown, L. J., Adlam, T., Hwang, F., Khadra, H., Maclean, L., Rudd, B., … Astell, A. J. (2016). Computer-based tools for assessing micro-longitudinal patterns of cognitive function in older adults. *Age, 38*(4), 335–350.

Brown, L. J., Adlam, T., Hwang, F., Khadra, H., Maclean, L., Rudd, B., … Astell, A. J. (2018). Computerized self-administered measures of mood and appetite for older adults: the Novel Assessment of Nutrition and Ageing (NANA) tool kit. *Journal of Applied Gerontechnology, 37*(2), 157–176.

Timon, C. M., Astell, A. J., Hwang, F., Adlam, T. D., Smith, T., Maclean, L., … Williams, E. A. (2015). The validation of a computer-based food record for older adults: the Novel Assessment of Nutrition and Ageing (NANA) method. *British Journal of Nutrition, 113*(4), 654–664.

Chapter 25
Learning Activity: Structured Brainstorming for the Co-production of Real-World Products

Carolyn Sparrey

The Challenge

Working effectively in diverse teams to generate ideas for solutions to real-world problems can be a challenge in any environment. Traditional group brainstorming, captured by clichés of “there are no bad ideas” and “think outside the box,” is often not effective at generating creative or practical solutions in a timely manner. Learning to develop structured brainstorming sessions will improve the productivity and output of your team. It is a myth that constraining the problem limits creativity. If the constraints are embraced, they can lead to better solutions, while fighting the constraints can limit creativity. Applying practical constraints to the brainstorming process and iterating solutions over multiple sessions can lead to better results. Importantly, while team brainstorming may not always be the most efficient means to generate solutions, the process can encourage buy-in from team members who participated in idea generation leading to quicker implementation and adoption.

The activity is to map a plan for a structured brainstorming workshop to generate solutions to your identified problem. In planning your workshop you should consider best practices of participatory design. This includes: constructing an appropriate brainstorming group including potential stakeholders such as academic and industry partners, end users, policy makers, funders, and others; defining the constraints for your solution space; and developing leading questions to facilitate discussion. The activity is intentionally broad to allow adoption for a range of applications.

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There are five key steps in this activity for a structured brainstorming workshop:

1. Define the problem to be addressed.
2. Constrain the problem.
3. Identify participants for effective co-production.
4. List leading questions.
5. Shortlist or reduce solutions to a top three.

To begin, you must first define the problem to be addressed. In defining the problem, it is important to think about the need, not the solution. For example, our need could be to develop solutions for addressing social isolation in older adults. We should not start by saying we need to develop an app to address social isolation. The method for solving the problem should be developed as part of the brainstorming process—not be dictated from the start.

Once the problem is identified, we need to constrain it to generate effective solutions. Examples of constraints may include budget, timeline, specific end users, functions, sustainability (both economic and environmental), team skills, and/or access to equipment or expertise. Listing the constraints provides important guidelines to a structured brainstorming group. However, care should be taken to not over-constrain the problem to fit a preconceived idea of the solution.

A key element of effective brainstorming is to have a diverse group of people participating in the activity. To develop the list of participants it is important to consider the range of stakeholders who could contribute to the solution. This could include academic and industry partners, nonprofit or community groups, clinicians, care providers, policy makers, health authorities, older adults, and/or people with a specific health or social condition. In assembling this list of potential participants, it is important to also consider the overall diversity of the group members such as gender, culture, age, ethnicity, and/or socioeconomic status to ensure you have a representation of the broader society.

To facilitate effective brainstorming in a diverse group of individuals, it can be helpful to provide leading questions to initiate and guide conversion and to draw individuals into the discussion. As the group facilitator you can direct these questions to individuals who may not be as vocal and these questions can assist in reducing the impact of a single dominant voice. Develop questions that are open ended and accessible and/or relatable for all members of your brainstorming group. To help spark ideas questions should focus on three key areas: (1) immerse yourself (have or imagine the experience for yourself), (2) challenge standard practices (e.g., what services would the government never pay for?), and (3) use analogies (e.g., how would Google address this challenge?).

Finally, the range of generated solutions must be reduced to a selection of top choices. Allowing for a top three (or five) can make the process simpler and less contentious than trying to find a single solution. Having multiple solutions also allows freedom to explore options and iterate solutions for more than one possible solution. If one solution is later found to be not feasible or practical after more comprehensive analysis, there will be a potential alternative without having to repeat the entire process. Saving the evaluation of ideas until after the idea generation phase is complete is important for supporting open, creative discussion. Remember to draw in all of your stakeholders using your leading questions *before* moving to the critique phase.

Remember that solutions generated at the end of a brainstorming session are only a starting point. Iterating through solutions and reporting back to the group on progress towards a solution are important follow-up steps after a brainstorming session.

After doing this activity, you should:

- Understand what is structured brainstorming.
- Be able to outline a structured brainstorming event.
- Be able to organize and facilitate structured brainstorming.

Learning More

- Girotra, K., Terwiesch, C., & Ulrich, K. T. (2010). Idea generation and the quality of the best idea. *Management Science, 50*(4), 591–605.
- Rosso, B. D. (2014). Creativity and constraints: exploring the role of constraints in the creative processes of research and development teams. *Organization Studies, 35*(4), 551–585.
- Capozzi, M. M., Dye, R., & Howe, A. (2011, April). Sparking creativity in teams: an executive's guide. *McKinsey Quarterly*. McKinsey & Company. https://www.mckinsey.com/business-functions/strategy-and-corporate-finance/our-insights/sparking-creativity-in-teams-an-executives-guide.

Supporting Materials

Template for Structured Brainstorming

In this example, we conducted a structured brainstorming activity involving several groups to address a range of challenges for older adults that could be supported by technology. When conducting structured brainstorming, remember to keep the group size to 6–8 members to maximize efficiency. It is recommended that for a larger group of participants that the participants be placed into multiple smaller groups. The target of this particular brainstorming session was to work towards a technology concept or idea that could be developed and tested within the provided constraints. Because this was a funded workshop, we were able to assemble a broad range of participants for the co-creation process. This may not always be possible, but it is encouraged. In this example, the structured brainstorming was scheduled for 3 h and included an opportunity for critical assessment and discussion:

1. Problem to be addressed: How to reduce social isolation in older adults in remote communities?
2. Constraints:

   (a) Solutions must fit within funding bounds (1 year, $50,000).
   (b) Must be possible with the skill set of the team or known collaborators.
   (c) Must address identified social challenge in some way.
   (d) Okay to only address one aspect of the larger challenge.
   (e) Must provide a feasible economic model for longer term sustainability (e.g., if technology is given away free, how can costs be covered?).

3. Identify participants for effective co-production:
   (a) Researchers/trainees.
   (b) Older adults.
   (c) Policy makers.
   (d) Health care providers.
   (e) Caregivers/family members.
   (f) Community organization.
   (g) Industry/company partners.
   (h) Funding agency.
4. List leading questions:
   (a) User experience:
      - How does the technology user go about his or her day?
      - How could/does technology be integrated in his or her life?
      - What format is most accessible/usable for the targeted end user?
      - What skills/expertise do targeted end users have?
      - How have you experienced social isolation?
      - Can you imagine what social isolation looks like for an older adult?
   (b) Stakeholder involvement:
      - How do health policies, funding, community, and industry affect social isolation?
   (c) Challenge standard practices:
      - What services would the government not pay for?
      - What level of health care do people expect?
      - Should wellness be part of health care?
   (d) Use of analogies:
      - How would Google address this challenge?
      - How would Tim Horton's address this challenge?
5. Finding your best solutions:
   (a) Write solutions on a poster board (whiteboard or other large surface).
   (b) Provide Post-it® notes to each group member to write thoughts, comments, or feedback on each idea (this works well to coincide with a coffee break and have people move around the room).
   (c) Take a walking tour to each poster board and revisit the solution in the context of the provided feedback.
   (d) Rank the solutions using the constraints to guide rankings.

Chapter 26
Doing Research Ethically

Judith Sixsmith and Andrew Sixsmith

The Challenge

Much of the research carried out in the health sphere will involve interacting with human subjects and will thus be regulated by research ethics boards (REBs; institutional review boards (IRBs) in the United States), in order to ensure the highest standards in terms of research procedures and to mitigate potential risks to participants. However, it is argued here that conducting ethical research goes beyond attending to ethical technicalities such as informed consent. Instead, ethics is a dynamic, shifting field of considerations (Kaye et al., 2015) embedded in projects that present their own unique ethical challenges that might emerge as the project progresses (see Box 26.1). Nontraditional research approaches, particularly participatory action research designs, also demand thinking differently about ethics (Goodyear-Smith, Jackson, & Greenhalgh, 2015). Consequently, it is the

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responsibility of everyone in a research team to understand and work proactively toward ethical research.

Box 26.1 An Ethical Challenge
In research exploring refugee and asylum seeker migrants' access to healthcare, researchers interviewed participants in places of their choice where they felt comfortable. One man elected to be interviewed on a park bench because, being homeless, the address of the park is what he used for official purposes such as registering at a general practitioner. During the course of the interview, he talked at length about his "ugly life," his insecurity, and loss of family that affected his health. Introducing his anxiety and depression into the interview, he said that after the interview, he was intent on taking his own life as nothing was now left for him. At that point, the interview was set aside, and his dreadful situation became the focus of attention. The list of support agencies the research team had identified if any migrants needed help was consulted and the address of a local acute mental health service located. With persuasion, the researcher accompanied the participant to the facility. The researcher waited with him as a concerned member of the public until he was assessed. The team then checked on him a week after the event. Immediately after the event, the researcher contacted their research "support buddy," another member of the team who was assigned at the beginning of the research to support this researcher in case of any difficulties. After meeting to talk through what had happened, the researcher was offered counselling support but felt this was not necessary.

This example points to several ethical issues: (1) preparing strategies and action plans to cope with support eventualities for participants; (2) setting aside the research where necessary to support distressed participants; and (3) attending to the support requirements of researchers by setting up a "buddying" system and ensuring access to professional services if required.

Key Ideas

Some General Principles Around Ethics in Research

All research needs to be conducted in accordance with the relevant REB guidelines and policies, as will be discussed. The basic ethical principle underlying any research with people is to protect their rights and well-being and to avoid causing them harm. Key ideas about ethics in research are presented below and are drawn from McCormick's (2013) article "Principles of Bioethics." We also provide some practical actions to help ensure ethical research.

Non-maleficence (First Do No Harm, Ensure as Little Harm to Participants as Possible)

The principle of non-maleficence is that we do not intentionally cause harm or injury to the research participant, either through acts of commission or omission. It is also negligent if the research involves a careless or unreasonable risk of harm upon another. Taking positive actions to minimize risk of harm is not only based on commonly held moral convictions, but by the laws and regulations (McCormick, 2013):

- All participants will be protected from harm and not be exposed to any risks other than they might meet in normal everyday life.
- Researchers will ensure that participants are left in a positive frame of mind as far as possible.
- An exit strategy should be designed and deployed so that researchers leave the research field in a positive way.

Beneficence (Duty to Ensure There Is Some Benefit to the Participant for Their Participation)

The beneficence principle holds that researchers have a duty toward benefiting research participants, as well as taking steps to avoid potential harms. These duties are seen as rational and "self-evident" and are accepted as key goals of research with human participants (McCormick, 2013).

- Participants will be treated with respect at all times and their confidentiality protected in terms of anonymity and privacy (see Box 26.3).

Autonomy (Right of Participant to Make Informed and Voluntary Decisions)

Participants in research are seen as having "the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act. This principle is the basis for the practice of 'informed consent'" (McCormick, 2013).

- Participants need to give their informed consent and not just in relation to the aims and/or objectives of the study but also concerning the process of the research, including how the research will be conducted, what their part in it would be, their time commitment, and what will happen with their data and the benefits of involvement.

- Participants will be empowered to withdraw from the research process at any time (up to a date which makes sense in terms of the research, see Box 26.2) and without incurring any sanctions.
- Pseudonyms or codes will be used to replace any identifiers within the data, and data should be kept safe in locked offices and/or under password protection.

Justice (Ensure Fairness and Participants Are Treated Equally)

Justice in research implies the concepts of fairness and entitlement, where it is thought that people as equals should qualify for equal treatment within the research process and that considerations of equity and equality should be considered in terms of the outcomes of research.

- If requested by the participant, a short report or a copy of their data (usually transcripts in qualitative research) will be made available. Participants may want to check their information or read about the results of the project.
- Finally, ethical protection of researchers should be considered, including the creation of a *lone worker* (Rinkus, Kelly, Wright, Dobson, & Medina, 2018) policy and *buddying* systems.

Box 26.2 Withdrawal from Research
Typically, ethical guidelines will require the researcher to allow participants to withdraw from the research "at any time." However, this can sometimes be very difficult in practice. In a Ph.D. study on the impact of being unemployed on the lives of middle-aged family men, just such a withdrawal agreement was made. Just as the thesis had been written for submission, a participant contacted the researcher 1 year after the interview to request that his data be removed given that, he said, he had been depressed at the time of the interview. His data had been critical to making an important point in the thesis. Nevertheless, the researcher went back to the analysis and subsequent findings chapter to remove all points related to this participant and reframed the analysis. This also required some rewriting of the discussion chapter. While this was possible, imagine if the request had come after submission of the thesis, or after the defence, and after the degree was awarded. Perhaps it is better to define a time period in the initial information sheet provided to the participant which clearly discusses a withdrawal agreement with the participant of when the participant data can be withdrawn rather than specifying "at any time."

Understand the Relevant Research Ethics Boards (REBs) for Your Study

There are several different names covering the organizations which can grant ethical approval to a research project: institutional review boards (IRBs); independent ethics committees (IECs); research ethics boards (REBs); and ethical review boards (ERBs). Despite different names, these have essentially the same function to provide ethical oversight of any research that involves people. REBs typically comprise a committee who review the purpose, methods, and procedures of a project to ensure that the research conforms to accepted ethical guidelines and policies so that participants' rights are protected and that they are protected from harm. REBs are the researcher's best friend, even if it doesn't always seem like that! Although REBs are often seen as a barrier to getting research done, they are an essential part of the oversight and governance in academic research.

Box 26.3 Quorum Review's Definition of an REB

A research ethics board (REB) performs the same function in Canada as an IRB does in the United States. An REB is a group of individuals responsible for reviewing a study to make sure that the research participant's rights and welfare are protected. Most clinical research studies cannot begin in Canada without REB approval. REB members generally include healthcare personnel such as doctors, nurses, and pharmacists. The REB also includes other members of the scientific community, nonscientists such as clergy or social workers, and community members. The REB carries out its responsibility to protect the rights and welfare of research subjects by reviewing the protocol to make sure that risks to participants are minimized, that risks are acceptable in light of the possible benefits, that the informed consent document is accurate and complete in describing the study and its risks and benefits, and that the clinical research study is conducted in an ethical manner. If the REB believes that these conditions have been met, it may approve the study and allow it to begin. Once the clinical research study begins, the REB is responsible for periodically reviewing the approved study to assure that the rights and welfare of research participants continue to be appropriately protected. Usually, the informed consent document will provide the research participant with a phone number to contact the clinical investigator or the REB if the participant has a question or concern about how the study is being conducted (Quorum Review, 2019).

One issue facing participatory and action-oriented research is that the approach and methodology need to be flexible. For example, getting user feedback on a technology requires a person to try it out with the researcher, observing and asking exploratory, open-ended questions. However, REBs have typically been created with conventional clinical-trial methodology in mind. Participatory design may mean that the intervention or technology may not have actually been defined at the start of the project. In these cases, it may not be possible to provide detailed information in an REB application until a later date. However, many funders require REB approval before funding is released—a Catch 22 situation! In practice, REBs will be responsive if you clearly articulate your general approach and describe your limitations. A good solution is to approach REB applications iteratively—set out the general terms of reference and approach as well as methods in an initial application to get things started, for example, you may be starting with visioning workshops. As a project develops and matures (e.g., as requirements or a prototype is developed), then submit a project amendment to the REB. This may not require submission to the full REB committee and may only require limited oversight and quick turnaround in practice. Also, prepare in advance a list of study instruments that may require submitting an ethics amendment at a later date. An amendment is a minor change to a project that does not change key aspects of the study design and is typically turned around speedily. If the researcher is organized and keeps an amendment list, this allows more flexibility to make any changes to the questionnaire, interview guide, etc.

Being Prepared

Returning to the idea that good ethics requires being proactive, there are a lot of things that a research team can do to avoid problems and anticipate challenges, including:

- Discuss your research ideas and methods with an advisory group.
- Develop an ethical protocol and share with the whole team (see Box 26.4).
- Put a procedure in place for researchers to report and discuss problems.
- Provide or attend training courses on research ethics.
- Keep ethical issues as a standing discussion point in team meetings and advisory groups.

Box 26.4 Ethical Protocol

The UK-funded SAPHE project developed an in-home sensor and monitoring system to help manage people with chronic health conditions. The team included multidisciplinary academic partners and four industrial partners. Some important ethical challenges arose in this project, as it involved a field trial of technologies that gathered individual health data from people’s own homes. Inevitably, this could be seen by some participants as an invasion of their privacy. In order to build a sound ethical way of working within the project, an ethical protocol was developed and that shared the outlined

(continued)

Box 26.4 (continued)

expectations of all research team members in their dealing with research participants. The ethical protocol also provided ideas and information on particular problems that might be encountered. For example, several of the research team members had no experience of working with people with dementia. Learning resources, personas, and scenarios were provided to help team members to get a better understanding. Also, this was important since the industrial partners were less well versed in research ethics than the academics. All members of the research team need to be fully aware of the governance procedures that are in place, i.e., in their institution or relevant jurisdiction. As well, project leads need to ensure that their projects comply with ethical standards and guidelines.

Ethics Requires Empathy

If you are working with human participants in a research project, then you will need to work with them as fellow humans and not as some kind of alien being. Treating people as research *subjects* actually makes them into objects, to be literally or metaphorically poked and prodded. Do not be surprised if you alienate people by this approach. Even if your project requires you to have a strict arms-length protocol (for the sake of objective science), you should still take time to do this in a sensitive way. All research with human participants needs to be done with empathy and sensitivity. Consider these points as they relate to your research:

- Research with potentially vulnerable people, such as frail older adults, needs to be done with attention to the limitations and preferences of the participant.
- Research with humans is dependent on the skills and personal qualities of the researchers involved. It is important that interviewers who are recruited to conduct interviews have the potential to work in this way. Specific training was given to researchers within SAPHE about interviewing techniques, procedures, and ethical issues.
- An interview might actually be a stressful situation for some people. The interviewer will be required to monitor the status of the participant during the interview in a process of continuous assent. Emphasizing that participants are experts on their own experience and that the researchers are there to learn from them can help build confidence.
- A process needs to be put in place where researchers can highlight any matters of concern arising from the interviews that can be dealt with in compliance with local social services procedures.
- Procedures are needed to deal with adverse effects, risks or hazards, pain, discomfort, distress, or inconvenience to the researchers themselves. For example, a list of support organizations can be made available to the participants and help given to contact them if needed.

Confidentiality and Anonymity

Ensuring the security and confidentiality of data is crucial. But confidentiality as a concept does not always translate well into the multiple understandings that different people hold. It is quite common for ethical protocols to assure participants of confidentiality. The problem with this is that in common language, many participants may understand *confidentiality* as *in confidence* or *keeping a secret*. Clearly in research, and particularly qualitative research, confidentiality does not mean *keeping a secret*, rather it has the more specific meanings of keeping private those aspects of the interview indicated by participants as private while maintaining their anonymity so that they cannot be recognized within any aspect of the research. By being clear with participants about the meaning of *confidentiality* in the context of research, direct quotations can be used in analyses, reports, articles, and teaching sessions, and the participants' stories are told without contravening informed consent. Nevertheless, maintaining *confidentiality* in terms of privacy and anonymity in research is important, and each researcher needs to ask key questions to ensure data is safe such as:

- What measures have been put in place to ensure confidentiality of personal data?
- How will data be stored securely?
- Where will the analysis of the data from the study take place and by whom will it be undertaken?
- Who will have control of and act as the custodian for the data generated by the study?
- Who will have access to the data generated by the study?

Data handling and protection is an integral part of maintaining confidentiality. Different issues arise depending on the medium in which the data is held, such as hard copy or electronically. For hard copy, keeping this in a locked desk in a lock room is often necessary. Electronic data should be encrypted and held in a secure location such as secure university repositories. Finally, data sharing is implicated here and should always take place using secure channels. Check with your REB to ensure compliance with data sharing and transmission requirements. Ensuring that data is not held longer than is necessary and is destroyed according to a strict ethical plan and securing that access to data is only possible for persons named in the ethical protocol should be carefully planned for and actioned.

Working with People Who Can't Give Consent Themselves

This is a tricky issue. While it is important that vulnerable people are protected, this has often meant that some people, such as people with cognitive impairments, have been excluded from research studies. This is a serious ethical impasse, as their exclusion may mean they consequently fail to benefit from new services, solutions, and technologies. Transdisciplinary research needs to be committed to an inclusive approach. An information sheet and consent form specifically aimed with cognitive limitations in mind should be developed, and attempts to gain written consent should be made in all cases. Where a person with dementia and their carer are interviewed together, they should both be asked to read the information sheet and provide consent. You can also read the information to the person. Typically, there is also an information sheet and consent form for carers and care professionals. Consent will be taken at the start of interviews and/or focus groups. The researcher is required to continuously ascertain whether the person is still willing to continue with interviews once they have started (Wang et al., 2016). However, working with people with cognitive impairments requires continuous ethical scrutiny such as:

- It is possible that despite the information provided and discussion prior to the research, the user subsequently becomes anxious or concerned about their involvement. In these circumstances the research will be terminated.
- It is possible that the person may feel inadequate or guilty if a test of equipment or a service shows there are still problems for the designer to address. If a test has these results, the team will take care to reassure the user as much as possible that the result was the problem of the designer and was nothing to do with them and that their role has been very important in highlighting the problem.
- The person may misuse a device. Even if the risk of this is minimal, it is important that the researcher responds appropriately.
- People may experience increased agitation and/or confusion with something new in their living environment. The research may be disruptive to the person's routine. Interviews may be stressful to the person with dementia. Researchers need to be sensitive to these situations and respond appropriately.

Particular attention should be given to the needs of people with cognitive impairments, in order to ensure that their needs are being addressed. Ethically, it was important that even participants with significant cognitive impairments are, as far as possible, actively involved in the research, that their perspective was heard and responded to, and that their human rights and civil liberties are promoted and protected. Solutions that are being designed were aimed at improving the quality of life of people with dementia, and without their involvement, it would not be possible to assess whether this aim had been achieved.

Dealing with Ethical Dilemmas

While there are key general ethical principles that apply to all research involving human participants, every project is likely to encounter its own ethical issues and dilemmas. It is important that the project and research team are prepared to respond to these challenges. For example, in a project that is designing or implementing and evaluating a new service or technology, it is often difficult to predict accurately how users will react to design solutions, and it is important to involve them in the design process right from the outset to try and avoid these kinds of issues. Prototypes should be regularly tested with intended users to get comment, to guide the progress of the new design, and to highlight any unpredicted problems. This user-led process has been shown by many researchers to work very effectively and to lead to successful new devices that have real-world benefits.

There are several ethical issues with applying this approach. It is implicit in the process that some of the prototypes tried out will not work totally effectively, and this may well cause distress for someone. In this context it is important to deal sympathetically with the user. Even with these precautions, there is a finite risk that a new device might cause an unfavorable reaction. To deal with this risk, it was crucial to the process that initial tests are kept very brief and undertaken with good support from a carer and care professional if appropriate. With any indications of anxiety or distress, the test will be stopped immediately. Consequently the procedure minimized risks as far as possible and dealt with unpredictable user reactions and are therefore felt to be acceptable given the potential benefit successful solutions would have for people.

Increasingly, the research team should be looking beyond the narrow confines of their project and think about how their solutions might be used in the real world. Typically, innovation is disruptive, while new technologies are often used in ways that might not have been intended. Discussing potential negative outcomes and impact should be part of the wider transdisciplinary approach and ongoing dialogue within the project team. Creating guidelines for the ethical use and the implementation of new solutions and technologies can be helpful. Longer-term impact evaluation can also help to highlight negative outcomes and impact (Table 26.1).

Box 26.5 Ethical Dilemmas in New Services and Technologies for People with Dementia

Research typically strives to be *objective*, but the outcomes or impact of research are not neutral. If it is expected that research will lead to innovation, then it is essential that technologies are visualized, developed, implemented, and evaluated in terms of their real-world impact. In an environmental scan of research on in-home monitoring technologies to support people with dementia, Sixsmith (2006) highlighted six ethical dilemmas relating to how new technologies might be used in care practice:

- Would technologies afford a wider range of services or just constrain choice in other ways?;
- Would they mean better home-based services or an inevitable loss of privacy and dignity?;
- Would services become more responsive to the individual or become more impersonal through the use of telecommunications?;
- Would new products meet the real needs of consumers, or would they simply reflect marketing strategies aimed at exploiting vulnerable people?;
- Would these technologies be empowering or contribute to increasing the dependency of the person?; and,
- Would any financial savings made through the use of technology be reinvested in products and services or would it be a cost-cutting exercise?

Table 26.1 Product innovation pathway (PIP) model—working ethically

PIP level	PIP description	Key activities
1	Innovative ideas	Make sure your stakeholder group includes someone or organization (e.g., advocacy group) that represents end users, especially if those people represent a vulnerable or marginalized group. Explore and discuss potential ethical issues relating to ideas and potential solutions with stakeholder group. Seek further advice if there are any outstanding ethical issues to be resolved.
2	Planning	Create a detailed project plan and discuss with the stakeholder group the possible ethical issues in the project. Refer to and include standard best practices: for example, data confidentiality, etc. Create necessary documentation: Information sheet, consent form, etc. Develop and submit project application to appropriate REB Create a checklist for possible amendments to study instruments. Give your funders plenty of notice if there are delays to the study. Some funders need IRB approval letter to start or continue the funding. Develop a project protocol that explicitly includes ethical issues and how to deal with them, planning for *unintended* as well as known eventualities. Ensure researchers complete training on ethics and research governance. Address research bias proactively—even if your project focuses on a particular group, ensure that inclusion criteria and recruitment procedures are fair and equitable.
3	Development	Review ethical protocols throughout the research process and deal with ongoing ethical issues as they arise, which may include referring to an advisory group or to REB. Suspend the project if a significant ethical problem is encountered until it is resolved. Log any potential ethical issues for discussion by stakeholder group. Make sure you have a procedure in place for team members to report any ethical issues that emerge and for these to be dealt with in an appropriate and timely way. Provide ongoing reports to REBs.
4	Testing in real-world environment	Carry out evaluation to determine use acceptability and any unanticipated outcomes or unintended consequences. Explore and evaluate with the stakeholder group any ethical issues that might arise. Develop guidelines for ethical deployment and use of the service or product.
5	Outcomes and impact	Carry out an impact study to look at potential negative and positive impacts of the intervention.

Finding Support

If you are part of a university, college, etc., it is highly likely that your organization has its own research ethics policy REB. Familiarize yourself with policy and procedures, attend training courses, and get to know the staff (who are usually very helpful).

If your project involves working with partner organization (e.g., health authority or service provider), then you may additionally be subject to their internal ethics review and procedures. However, there may be a streamlined or unified REB in place. These sources offer a solid foundation of knowledge to consult:

- NRC Research Ethics Board: https://www.nrc-cnrc.gc.ca/eng/about/ethics_integrity/research_ethics_board.html
- Research ethics library: https://www.etikkom.no/en/library/
- Principles of bioethics: https://depts.washington.edu/bioethx/tools/princpl.html#prin4

Key Messages

Doing research in an ethical way and following accepted standards of good practice not only protects the rights and well-being of participants but will also contribute to doing a better job overall:

- REBs are in place to provide oversight of any project that involves humans and human data, in order to ensure safety and protection of rights.
- Ethical research goes beyond technicalities, as any project will present its own unique ethical challenges.
- It is the responsibility of everyone in a research team to understand and work proactively toward ethical excellence.
- Working with vulnerable groups may present significant ethical issues.
- Ethical research requires empathy and sensitivity.

References

Goodyear-Smith, F., Jackson, C., & Greenhalgh, T. (2015). Co-design and implementation research: Challenges and solutions for ethics committees. *BMC Medical Ethics, 16*(1), 78.

Kaye, J., Whitley, E. A., Lund, D., Morrison, M., Teare, H., & Melham, K. (2015). Dynamic consent: A patient interface for twenty-first century research networks. *European Journal of Human Genetics, 23*(2), 141–146.

McCormick, T. R. (2013). *Principles of bioethics*. Washington: University of Washington School of Medicine. https://depts.washington.edu/bioethx/tools/princpl.html#prin2.

Quorum Review. (2019). What is a research ethics board (REB)? https://www.quorumreview.com/qa_faqs/research-ethics-board-reb/.

Rinkus, M. A., Kelly, J. R., Wright, W., Dobson, T., & Medina, L. (2018). Gendered considerations for safety in conservation fieldwork. *Society & Natural Resources, 31*(12), 1419–1426.

Sixsmith, A. (2006). New technologies to support independent living and quality of life for people with dementia. *Alzheimer's Care Quarterly, 7*(3), 194–202.

Wang, X., Yu, X., Appelbaum, P. S., Tang, H., Yao, G., Si, T., … Ma, Y. (2016). Longitudinal informed consent competency in stable community patients with schizophrenia: A one-week training and one-year follow-up study. *Schizophrenia Research, 170*(1), 162–167.

Chapter 27
Ethics of Health Research and Innovation

Rosalie H. Wang and Jerome Bickenbach

In this chapter, we are concerned with the ethical dimensions of health research and innovation development and implementation. Ethics, or moral philosophy, is the investigation of principles and normative standards that guide people in making practical decisions and carrying out morally acceptable actions, all things considered. Biomedical ethics is concerned with ethical issues arising within biological and medical science as well as in health-care research and practice. By health innovation we mean any advance in the science or practice of health care or health science that advances our knowledge and improves the outcomes of better individual and population health and well-being. Principlism, as proposed by T. L. Beauchamp and J. F. Childress, involves the moral principles of autonomy, beneficence, maleficence, and justice and dominates the traditional western framework (Beauchamp & Childress, 2009). More recent discourse in health ethics has expanded the range of traditional principles to address critiques of principlism's lack of comprehensiveness and its inadequacy in supporting decision-making (Bermúdez & Seoane, 2016). In contrast, and not without their own critiques, dominant European health ethics frameworks place prominence on the principles of autonomy, dignity, integrity, and vulnerability, which may reflect important sociocultural, political, legal, and historical differences between the regions (Bermúdez & Seoane, 2016).

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The Challenge

Here we address the challenge in health research and innovation ethics created by the mistaken belief that ethical considerations are complicated, impractical, and idealistic. It is often perceived that ethical concerns are merely troublesome hurdles that stand in the way of research and innovation. Additionally, it is sometimes thought that ethical concerns are idealistic and should only be addressed after all technical and practical challenges of innovation development have been solved. By contrast, we argue that ethical considerations are everyone's responsibility. This is especially the case when the research's aim is to develop and implement technology products, services, or policies. Thus ethical scrutiny is essential in all steps, from basic to applied research to product or service development and commercialization, service delivery, and policy implementation. Ethical considerations are not an afterthought, and ethical decisions must be both practical and reasonable. Moreover, everyone is an expert in ethics.

Key Ideas

Everyone Is an Expert in Ethics

Ethics does not require special skills or a privileged knowledge of theories, terminology, rules, or formulas. However, ethical deliberation in research and practice does require thought, good faith, and determination. There are no ethical algorithms that make deliberation easy and certain. Moreover, balancing competing ethical considerations is unavoidable: we need always to try to design, for example, innovative technological interventions that provide great benefit but do not undermine autonomy and ensure privacy without sacrificing efficacy. By their nature, ethical principles tend to point us in different directions, and we need to balance them. The objective in decision-making guidance is not, therefore, to be prescriptive or to assume there is one right answer. What is essential are open and honest discussions that include everyone who has an interest at stake and conducted against a background of the best available information and in a transparent and inclusive manner designed to define issues and challenges, to offer potential courses of action, and to decide on a workable resolution.

In this chapter, we introduce the salient principles of ethics that are the most clearly involved in the ethical conduct of human-oriented research and survey versions of these principles most relevant to ethical deliberation in health innovation and implementation. Our aim is to sensitize readers to these ethical principles.

Box 27.1 Ethical Considerations in Developing Innovative Technological Interventions

In technology product and service development, ethical principles can be at odds and require careful consideration of each application developed, the users involved, and the contexts in which they are applied. In developing an in-home monitoring and communication system with the goals of helping seniors to remain living at home safely and to maintain contact with their loved ones, for example, ethical considerations of autonomy, privacy, and efficacy are needed from the innovation's conception to its delivery. The availability of such a system can enable seniors to have more autonomy to choose where they want to live with increased safety. However, if they perceive that such a system keeps them under surveillance by family members or if the system records intimate information about them that may be viewed by others, seniors' privacy may be violated. If, for the efficacy of the system to ensure safety, seniors cannot control or customize when or how they are being monitored by their family or others, then seniors may have their autonomy restricted with a system's use.

Ethics in Health Research Is Everyone's Responsibility

When conducting health research for the benefit of people, ethics is everyone's responsibility. Researchers always have an obligation to conduct their work honestly and within professional standards, to carry out research with rigor, and to disseminate results widely. These are basic ethical considerations. For their part, public or private institutions have responsibilities to their researchers both to guard their academic freedoms and to ensure ethical, scientific, and professional norms are respected. Research implies exploring unknowns. It will always entail risk to individual participants or social groups—risks of physical, psychological, or other forms of harm. This risk may be minimal (e.g., inconvenience) or severe (e.g., physical harm or death). Research also promises direct or indirect benefits that can be balanced with these risks. Ethical principles and guidelines support how we balance benefits and risks in research. In Canada, the *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) is a policy that describes principles of ethical deliberation that can guide the conduct of health research (Canadian Institutes of Health Research et al., 2014). The TCPS2 was developed by the Interagency Advisory Panel on Research Ethics and is supported by the Secretariat on Responsible Conduct of Research and the three Canadian research agencies: Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council (SSHRC). The joint TCPS2 policy has been adopted by the three agencies. For every jurisdiction in which research is funded and carried out, these ethical principles augment the more explicit national and international laws and regulations in place to protect research participants' rights, including specifically informed consent (and the capacity to consent), privacy, and confidentiality.

Health Research Ethics Involves Three Core Principles

Research policies such as the TCPS2 are underpinned by the core ethical principles of (1) respect for persons, (2) concern for individual well-being, and (3) justice across a population. These broad principles correspond well with research ethics principles and policies found in other countries and internationally. The link between these three principles is a basic respect for human dignity, which entails that research should be "conducted in a manner that is sensitive to the inherent worth of all human beings and the respect and consideration that they are due" (Canadian Institutes of Health Research et al., 2014, p. 6).

Autonomy—the recognition that individuals have the right to make decisions about themselves and actions made upon them—is at the core of respect for persons. Respecting a person's autonomy is demonstrated by deferring to the individual's judgment and seeing that the individual has the freedom to deliberate and carry out desired actions. Protecting people's autonomy means, in research, providing information to and requesting consent from research participants and being accountable for and transparent about the nature and objectives of research activities. Autonomy, as it is reflected in the value of respect for dignity, is also expressed by the concern for privacy and confidentiality of information.

Box 27.2 Capacity and Consent to Research in Canada: Law and Ethics
Canada is a signatory of and has ratified the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) that mandates, among other things, that research conducted on individuals with, for example, compromised cognitive capacity (e.g., an older person living with dementia) have the right to insist on giving or denying consent to participate in research with *supported decision-making*. This means that the current Canadian law across all provinces, which tends to require a guardian to give substitute consent in these cases, will have to be modified, in time, to align with the United Nations' standards. This is a rare example where law and ethics may conflict, since legal obligations seem to be in conflict and practice requires ethical deliberation to decisions which legal provision will be applied. Currently this is an unresolved issue, but researchers in Canada will eventually find it necessary to take an ethical stand to respect autonomy according to the CRPD or to respect existing national legislation and regulations.

Concern for individual well-being addresses the overall quality of life of individuals across the realms of physical, mental, and spiritual health, paying attention in particular to the physical, social, and economic circumstances that shape these experiences. The concern for well-being is expressed in research by the balance between benefits and risks. Clarity about the benefits of research, either directly to the individual or indirectly to the population of which the individual is a part, is key to research ethics as is the realistic assessment of the potential for the risk of direct or indirect harm to an individual or others around them in the conduct of the research.

Lastly, justice is a matter of treating people fairly (ensuring that all receive the same respect and concern) and equitably (ensuring that the benefits and burdens are distributed to people as equals). Importantly, being equitable may entail treating people or distributing resources differently, when people are in different situations and unequal treatment or distribution creates an equal outcome. In health research ethics, consideration of the vulnerability of individuals or groups is an essential aspect of justice. A person or group is considered vulnerable if they experience restrictions owing to decreased decision-making ability, autonomy, power, and opportunities or rights. These factors' affect and are affected at every stage of research from the conception of a study to the dissemination of its results. Inequity can arise when individuals or groups do not receive benefits from research, for example, if their issues are not researched or if they are excluded from research participation for reasons that are not related to the research itself.

Box 27.3 Justice as Equity
Suppose two people need to go to the second floor of a building. If one of the two is in a wheelchair, it is inequitable to *treat both people the same* and require them both to use the stairs. Equity in this case actually requires treatment that is different. Equity requires that both people be able to reach the second floor and that means that the person in the wheelchair needs access to an elevator.

Key Idea

Developing Ethics Applications for Review and Approval Takes Understanding, Familiarity, and Practice

The process for developing ethics protocols and acquiring research ethics board approval for health research is often perceived as an arduous, complicated, and even troublesome hurdle to conduct research. Internationally, research requiring ethics review and approval is research that involves live humans or human materials, live or not (e.g., embryos, tissue samples). As a rule, research that only involves data for secondary analysis that is publicly available and legally accessible to the public—data in which there are no privacy concerns—or, for example, data that is anonymously collected (e.g., from observing people in public spaces) does not require an ethics review. Studies done for quality assurance or improvement, or studies that are effectively program evaluations, also do not require an ethics review.

Review boards will examine the research to evaluate whether the potential benefits justify the anticipated risks and, in any case, whether these risks can be eliminated or minimized. Risk for potential harm to individuals or groups may be social, behavioral, psychological, physical, or economic. Risk is evaluated based on the harm's magnitude or seriousness and the probability of the harm for participants or others. The level of scrutiny of the review depends on the degree of risk involved with the potential of physical harm or death demanding the highest level of review. Research involving minimal risk (i.e., risk that is no more than what people may experience in daily life) usually undergoes a delegated review by one person, rather than a full board review often involving two or more expert reviewers in the related field and a vote by a review board. Benefits may include direct or indirect positive contributions to individuals or to society as a whole. The board will consider the ethical impact of the research over the entire course of the project, as well as any residual effects after the project is completed, and will rely on all three ethical principles.

The procedures and outcomes of research ethics review boards are governed by the local requirements and institutional processes of the organization that houses the review boards. These institutions need to be consistent in their determinations and required documentation. When developing the application form, it is essential to be familiar with these requirements; but as these requirements may change from time to time, it is prudent to ensure that you receive up-to-date information. It is useful to take advantage of specific training or coaching from an experienced researcher on the ethics review process and associated local procedures. Looking over previously approved submissions may also help to better understand expectations.

Ethics in Health Research and Innovation and the Product Innovation Pathway Model

Unlike applications to research ethics boards, the broader area of research ethics is less prescriptive and procedural. It is, however, crucial to ensure that consideration of ethical principles is embedded throughout the pathway of product innovation development and implementation. For this reason, the Product Innovation Pathway (PIP) model can be used when planning and managing a project to indicate key areas in the pathway wherein ethical principles need to be considered and practical activities related to health research ethics need to be carried out (refer to Table 27.1).

Table 27.1 Product Innovation Pathway (PIP) model—ethics in health research and innovation

PIP level	PIP description	Key activities
1	Innovative ideas	Concept/idea generation, development of product goals/vision Consider who are the users (research participants and innovation consumers) and engage them (individually or in a group, e.g., advisory group) in identifying problems and concepts—consider issues of respect, welfare, and justice. For example, are they vulnerable in any way; are users or groups of users unduly excluded; are they meaningfully engaged; are researchers accountable following consultations; what are the benefits/risk of harms in the engagement process Consider concepts/ideas and whether the goals/vision of the products create benefits (e.g., enhance autonomy, independence, and inclusion) and what risk for harms there may be
2	Planning	Concepts/ideas defined, product proposals/plans created Similar considerations as in level 1 and related to considerations of respect, welfare, and justice, for example, are users' needs, values, and preferences transparently incorporated into development processes/solutions; are users' capabilities and changing abilities and environmental contexts taken into consideration; are any groups privileged in how competing needs, values, and preferences are addressed; how are benefits and risk of harms balanced; are any potential users excluded and why Become familiar with research ethics board application requirements; prepare application for submission, consulting with board as required for guidance and support
3	Development	Concepts/ideas refined, prototypes created iteratively Similar considerations as in levels 1 and 2, and in iterative prototype creation, consider issues of respect, welfare, and justice. For example, how is user feedback or new knowledge integrated into prototypes to maintain transparency and accountability; do the prototypes reflect the targeted benefits and eliminate/minimize risk for harms Prepare the research protocol application for submission, consult with board as required
4	Testing in real-world environment	Users recruited to evaluate prototypes in suitable contexts, variable evaluation types, use cases, and evaluation measures Similar considerations as above with respect, welfare, and justice and with research ethics board approval, proceed with participant recruitment, following approved protocol strictly, adhering to ethical processes related to informed and ongoing consent, research protocol fidelity, and respecting privacy and confidentiality, e.g., by managing data securely and confidentially, managing risk of harm, monitoring for incidents
5	Outcomes and impact	Document changes in targeted outcomes, explore effects in target areas, variable outcomes/impact depending on the measure of evaluation or deployment Similar considerations as above, and disseminate research findings

Resources

Key resources include policy frameworks relevant to completing research ethics applications within your jurisdiction. In Canada, the TCPS2 policy is a helpful (if not mandatory) reference, and the accompanying tutorial is a highly recommended resource (available at https://tcps2core.ca/welcome). Additional guidance is also commonly available directly from the local institutional research ethics board. Readers interested in the underlying philosophical aspects and principles of biomedical ethics are referred to the most recent seventh edition of Beauchamp and Childress' book, published in 2012, and Bermúdez and Seoane's book, published in 2016.

Key Messages

- Ethical deliberation is everyone's responsibility, although it is neither simple nor effortless but takes thought, good faith, and determination.
- At the heart of research ethics is the need to balance the key ethical principles of respect for persons, concern for individuals' well-being, and justice across the population.
- Underlying these three principles is the importance of respect for human dignity.
- In practice, research ethics tends to focus on questions of ensuring the autonomy of research participants (by informed and ongoing consent and guarantees of privacy and confidentiality) and treating all participants in research fairly and equitably.
- Research ethics boards are governed by these same ethical principles but because of institutional constraints tend to be far more prescriptive and procedural than research ethics are more broadly understood.

References

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics* (6th ed.). New York: Oxford University Press.

Bermúdez, P. S., & Seoane, J.-A. (Eds.). (2016). *Bioethical decision making and argumentation* (Vol. 70). Cham: Springer International Publishing.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). *Tri-Council policy statement: Ethical conduct for research involving humans*. Ottawa: Secretariat on Responsible Conduct of Research. http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf.

Chapter 28
Design Tools: Transforming Ideas into Products

Piper J. Jackson and Amy S. Hwang

The Challenge

A great idea is only the beginning of a project. To be successful, that idea will have to be designed, developed, and shared in such a way that it is accepted and used by the wider public. This is true of health innovation and broadly in other health-related fields. Therefore, it is important to acknowledge the critical role of the people who will use the outputs of the project by taking appropriate steps toward addressing their needs throughout the project life span. Part of this is simply accepting that people differ in many ways. Such differences can include age, gender, ethnicity, occupation, and many other factors that render individualized preferences, goals, and problems. Indeed, a single design based on our own assumptions and biases that is intended for an ambiguous target audience is likely to encounter many obstacles when it is used by people outside of the project team. However, there are well accepted and trusted tools for discovering user characteristics and concerns and incorporating them into a project focused on innovative design, development, and/or discovery.

In this chapter, we present the following key ideas:

- Personas.
- Scenarios.
- Use cases.
- Stakeholder involvement.

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Each of the tools we describe can be used on its own or in a synergistic manner with one another. These tools are valuable because they are aimed at facilitating the representation of the diversity of people and their experiences; enabling understanding and communication that spans different fields of expertise and knowledge; and focusing on producing successful products (Levina & Vaast, 2005). Aligned with the objectives of this book, these tools are exemplars of *transdisciplinary working*—an approach that prioritizes taking great ideas toward generating real-world impact.

Key Ideas

Personas

A persona is a description of a fictitious individual based on data gathered from real stakeholders (Adlin & Pruitt, 2010). Personas are used in product design and development to help identify user needs and priorities. Personas can be viewed as a tool for considering how a product might be used, particularly in any potential problems one might encounter during usage. Personas are intended to promote our empathy with the people for whom who we are designing a product. While each of us may hold different subject matter perspectives, personas help tap into our innate human tendency to generate detailed and complex models of people and their behaviors, even when those people are fictitious. This is demonstrated by the way we naturally try to relate to or develop understandings about fictional characters in stories or films. Using personas in the design process can help tap into this natural human aptitude that we all possess.

Personas facilitate design both as a collaborative process and as a practical tool. They help cross-disciplinary or cross-functional teams discuss and reach consensus regarding which consumers, stakeholders, or *users* for whom the designed product or service is intended. Personas reflect the team's decisions, represent their shared understanding of users, and behave as concrete tools in design, evaluation, and marketing (e.g., defining functional and user specifications, evaluating usability or user experience (UX), segmenting the target market). They provide concrete representations of hard-to-reach or disenfranchised user populations. Finally, they are useful when large or multidisciplinary development teams demand heuristics for efficiently communicating and translating complex information about users.

A persona should include characteristics relevant to your interest as a designer or developer (such as attitude toward technology, regular activities, usage patterns) and information that brings them to life—meaning personal attributes and circumstances that others can relate to. The latter includes the name of the person depicted by the persona, as well as demographic information, individual goals and preferences (e.g., hobbies), aspects of their personal history and present situation, and possibly an

Box 28.1 Example Persona

Kenjiro Tanaka

“Ken,” 72 years old, lives with his wife in a Burnaby apartment. They have a son who lives in Vancouver with his wife and two kids, but they only come for dinner once a month. Their daughter lives in Toronto with her husband and their baby boy, and they visit a few times each year. Ken retired eight years ago from working as an automotive engineer. Life has been boring ever since: his wife keeps busy with her church and volunteer friends, and his own friends recently died.

Health: Ken was diagnosed with mild cognitive impairment after his wife noticed his forgetfulness. He assumes this is normal for his age but feels frustrated when he cannot remember simple things. His wife convinced him to stop driving so he has been trying to get comfortable with the local buses.

Routines: Ken takes care of the groceries. Now that he does not drive and fears losing his way, he sticks to the same store on a familiar bus route. He goes during quieter times because he feels anxious and distracted by crowds—it is hard enough to keep track of his shopping list.

Goals: Without friends to visit, Ken wants to get more active and social, and heard this might even help with his memory. It is just hard to know what programs are available. His daughter bought him an iPad, but it came with no instructions and he will not burden his kids with trying to teach him. Maybe he could find a class with other seniors.

image or photograph. Box 28.1 provides an example of a persona. These elements serve two primary functions. First, they make the persona unique so that it represents a memorable individual rather than perhaps an unfounded stereotype of a group of people. Second, the persona engages the imagination of those who will use the persona, helping them to infer other information, such as how the personified might behave in a given situation or use a particular product.

While constructing a persona is partly a creative process of describing a fictitious individual, it can also be scientific insofar as employing a systematic creation process and synthesizing information from a variety of sources that include both qualitative and quantitative data (e.g., demographic data, research reports, surveys, interviews, observations, or electronic data). Although its basis in data is what validates a persona, it can also be useful and time effective to generate *assumption personas* that are based on designers’ assumptions or knowledge to date about their users. This is because the process of constructing a persona makes explicit one’s biases and assumptions about their target users. Particularly when undertaken as a team, this process can highlight different understandings between team members and user aspects that might require further knowledge gathering before proceeding in the design process. In these ways, grounding personas in a wide variety of data and generating assumption personas mitigate stereotyping the target user group(s).

Scenarios

Scenarios are stories of user experience: they describe a setting or situation in detail in which a person performs a sequence of actions (possibly involving other people), as well as the outcome of those actions (Carroll, 2000). For this reason, scenarios can describe how or why someone does something a certain way today (i.e., a scenario of reality) and how they might do something using a potential product or service (i.e., a proposed or future scenario). Generally, scenarios include information about the setting or situation, the person or people involved, their goals or objectives, and a *plot*—a sequence of actions or events. The level of detail for each of these elements, however, may range from evocative to prescriptive (Adlin & Pruitt, 2010). That is, a more *evocative* scenario may describe context and human motivation as a story-like narrative (see Box 28.2), whereas a more *prescriptive* scenario may describe a user's interaction with a particular system as a factual sequence of actions and/or decisions. Striking a balance between evocative and prescriptive, a scenario can also be represented (often using sticky notes) as a series of actions with comments (e.g., context notes, user's motivations for the action) and questions (e.g., Does the user do this [action] sometimes or all the time?) that pertain to each action. This is called design mapping, and it can be useful at different steps of research, design, and development to document and explore the proposed user experiences of a new product or service (Adlin & Pruitt, 2010).

Box 28.2 Example Scenario
Title: Ken Finds an iPad Class
Context: Ken has been looking around for a computer class to learn how to use his new iPad—he knows his son and daughter don't have the time to teach him, and he doesn't want to burden them. He asked at the local community center, but their program just finished, plus he does not see many seniors there, and the young people do not seem very approachable. His wife's friend told her about a community center in east Vancouver that runs a new iPad program. She gives him the community center's telephone number to call.

The next afternoon, Ken telephones the community center to ask about the program. The receptionist speaks very quickly, and he has trouble listening while writing down all of the information. She mentions "The information is all on the website" but then realizes that will not help him and encourages him to come to the center or have someone print out the details for him, hurrying him off the telephone. He manages to scribble down the address (a 30-min bus ride away), class dates (8 weeks, starting 1 week from today), and cost (reasonable, payable by check). After hanging up, he realizes he must figure out how to get there and what to bring or prepare (e.g., charge the iPad) and also worries, "What if everyone else knows how to use a computer and the Internet already?" Maybe he should call his daughter or daughter-in-law.

Scenario building can require even more creative effort than developing personas, as details, events, and interactions in the narrative need to be fleshed out and described in more detail. However, even here it is important to base as much of the scenario on data as possible to ensure its validity. For example, generating a scenario based on one single case study—no matter how richly informative the case—raises the question of whether that scenario applies across multiple people (or personas). As with personas, data should be gathered from multiple sources for greater rigor. *Use cases* or other task analyses being conducted for the project may also be considered as valuable sources of data. In fact, scenarios and use cases can provide valuable feedback for one another, developing in tandem (when worthwhile) through the life of the project. A use case can be used as the foundation of a scenario, providing the skeleton (in the form of actions) around which details can be fleshed out (such as the context and the people involved). Likewise, a scenario can provide validation for a use case by illustrating a believable instance of that use case and even suggest revision if the use case seems unlikely or lacking after reviewing it as a scenario. Scenarios can also be used on their own for evaluation by means of considering the *face validity* of the design in a given scenario: Would it work? What problems would different users face in different contexts?

Scenarios are a powerful tool during design and development for several reasons:

- They are widely accessible and efficient and are not dependent on having technical skills or special tools.
- Storytelling is a traditional and universal mode for sharing information and making scenarios useful for sharing ideas across disciplinary boundaries.
- Since the content of a scenario is only limited by imagination, they allow teams to discover and focus on primary issues rather than technical details when needed.

It is important to note that scenarios are not only driven by the creativity of their authors; readers are also able to draw upon their own knowledge and perspective when considering a scenario. This means that key issues can be identified for consideration very early on in the design process. Certainly, a scenario is not as rigorous as an engineering blueprint or a software specification, but that is entirely the point: scenarios are employed when flexibility and creativity are the priorities. They are a way of solidifying ideas into some definite shape by putting them down on paper. In doing so, they make decisions and assumptions more explicit. Scenarios are also efficient because they do not require the product to be built or finished, and they can be changed simply by editing text, rather than reengineering a system. When they are successful at illustrating part of the project focus, the elements that comprise the scenario content can be used to guide technical decisions. In this way, developing scenarios can assist ideas to move along the path toward becoming a rigorous specification because they allow implications of the ideas to be considered in more depth by facilitating discussion with a variety of team members and stakeholders.

Use Cases

Use cases are a technique originating from software engineering that are used for identifying and describing the interactions that take place when a system is used (Kulak & Guiney, 2012). Use cases focus on the goals and behaviors of the entities (including both people and machines) involved in a system while avoiding details such as the specific implementation of a technology. Use cases can be generated as a diagram which identifies the system itself, external actors (humans and other systems) which interact with the system, actions, goals, and relationships. They can also be generated in text format, which includes a description of the steps and possible outcomes of a task or interaction. They can also list other characteristics of the use case, such as the level of abstraction, which actors are involved, their goals, the scope of the system, triggers leading to the use case, events that will guarantee success, and conditions that must be true before the use case begins (preconditions) or will be true afterward (postconditions).

Box 28.3 Example Use Case
Use Case Name: Calling About Programming
Summary: A person interested in training programs available at a service agency telephones to find out relevant information. A receptionist answers the call and provides answer to the questions.

Basic course of events:

1. The caller telephones the service, and their call is answered by the receptionist.
2. The caller asks for details about programs: What is available? When does it begin? What are the requirements and/or costs?
3. The receptionist responds with relevant information, consulting written resources (e.g., webpage, manual) when necessary.
4. The caller writes down the information they are interested in.

Alternative paths: The receptionist could refer the caller to the website for information.

Exception paths: If the caller has difficulty writing and also has no access to the Internet, then they may have difficulty recording the information they are interested in.

Assumptions: The caller knows the contact number of the service agency and has access to a telephone.

Postconditions: The caller has the information necessary to make a decision about participating in programs provided by the service agency.

Use cases abstract away many details, leaving a generalized description of a system interaction devoid of the specific experience of any individual user. This is very useful for system developers because it allows them to develop a technical implementation with functionality that meets those clear interaction requirements. However, this means that use cases must be constructed carefully to ensure that they correctly represent, at a general level, the core interactions experienced by the unique individuals that compose the users of the system. Ongoing comparison and feedback using other design constructs, such as personas and scenarios, can help to validate a new or altered use case.

The use case technique fits well with the larger Unified Modelling Language (UML) framework for specifying software systems. This is not surprising, since they share a founder and key contributor (Ivar Jacobson). Within UML, there are specific diagramming styles for use cases, as well as other diagram styles and modelling methods for describing different aspects of system use, such as the sequence diagram for capturing when actions take place. These can be very helpful when used in conjunction with use cases, but these tools are meant to support design and not dominate it so it is necessary neither to adopt all of them in a project nor to follow their rules in a rigid manner.

Stakeholder Involvement

Stakeholders are involved most prominently in this process as the ground source of knowledge upon which these tools are built. While creativity takes a part in their construction, they do not produce value out of thin air. To be trustworthy and effective, they must be based on good data. It is important to collect stakeholder data to provide a foundation for the constructs developed using the tools. Multiple types and sources of data can be valuable, for example, the demographic profiles of key user groups can be identified using quantitative methods, while user goals and behavior can be captured using qualitative inquiry. This data gathering process can either be completed in advance or (preferably) done as part of an ongoing data gathering and feedback process. Pursuing data gathering in tandem means that ideas and questions that arise during the user and task modelling process can be addressed by users in a subsequent stage, and then feedback can be used to further develop a model or provide validation for some or all aspects of the model.

Stakeholders can also make important contributions in other ways. They can be directly involved in the creation of personas, scenarios, and use cases in a process called co-creation (Sanders & Stappers, 2008). In collaboration with project members, stakeholders can generate ideas, consider assumptions, and answer questions about relevant values, context, and actions. They may also become involved after design tools have been constructed in order to provide validation or valuable criticism. With knowledge built up from lived experience, stakeholders are particularly suited for judging whether a persona, scenario, or use case corresponds to someone or something that could be encountered in real life. They provide a complementary source of insight and authentic perspective invaluable to the whole process (Table 28.1).

Table 28.1 Product Innovation Pathway (PIP) model

Product Innovation Pathway (PIP) model—personas, scenarios, and use cases		
PIP level	PIP description	Key activities
1	Innovative ideas	Iteratively gather user information through questionnaires, interviews, observation, etc. to develop and test your ideas and to develop a good understanding of the stakeholders, their experiences, and the context in which your product will exist. Assumption personas can be constructed and used to formulate questions
2	Planning	Construct personas, scenarios, and/or use cases to support ideation and decision-making during design. Continually test your constructs to test their validity and adapt or build new ones in tandem with new design ideas and decisions. Co-creation sessions can be held to directly involve users
3	Development	Use cases can be used to specify product implementation. Personas, scenarios, and use cases can be used to check whether specifications match stakeholder needs as well as desired usability and user experience outcomes
4	Testing in real-world environment	Constructs can guide testing design and can be contrasted against real-world results to evaluate quality and accuracy
5	Outcomes and impact	Developed constructs can be used to communicate the product, e.g., in advertising and instructional material. Constructs can be used for ongoing development, such as changes in distribution or user interfaces

The tools presented here help good ideas materialize into successful products. They are used most often during planning and development (Levels 2 and 3 of the Product Innovation Pathway (PIP) model). They also support project managers and leaders when critical decisions need to be made, such as refining the focus of the product, solving concrete implementation details, and determining how best to get the product out to its target audience. These tools have been included in various life cycle models, such as ISO 9241-210: *Ergonomics of human-system interaction—Part 210: Human-centred design for interactive systems* (ISO TC 159, 2010), as well as the Agile UX and Lean UX approaches to development. These life cycle models emphasize iterative collaboration, so that it is possible to learn and correct mistakes while the project progresses. They also emphasize the importance of considering users and other stakeholders from the very beginning of development. Agile UX envisions ongoing interactions between a design/data gathering team and a technical implementation team, such that the outputs and questions from each team can lead each other's subsequent efforts (Sy, 2007).

It is important to point out that these are products of the development process *in their own right* and can be found in use outside of their originally intended context. For example, at Microsoft personas "are seen everywhere and used broadly" (Pruitt & Grudin, 2003, p. 9). They can also be used entirely outside of development, such as a tool to illustrate research findings (Council of Canadian Academies, 2017). Personas, scenarios, and use cases capture information about users and their activities in a way that is not only widely accessible but also widely applicable. With their emphasis on efficiency, project success, and meeting the needs of users and stakeholders, they are a useful addition to the health innovation toolbox.

Learning More

This book chapter is only an introduction to the complex world of translational research. Further information on working with personas, scenarios, and use cases can be found at:

- Systematic methods for creating both assumption and data-driven personas are available in Adlin and Pruitt's *The Essential Personal Lifecycle: Your Guide to Building and Using Personas* (2010). Similarly, there are books providing in-depth descriptions of how to build scenarios (e.g., Carroll, 2000) and use cases (e.g., Kulak & Guiney, 2012).
- There are many useful websites and courses available online focusing on design methods and approaches. Some examples are opendesignkit.org, interaction-design.org, uxdesign.cc, udacity.com, and ideo.com.
- Local meetup groups on user experience (UX) design and healthcare technology design can be a great way to meet local experts and share information.

Key Messages

Personas, scenarios, and use cases are:

- Widely used tools for producing successful products.
- An effective and efficient way for developing and testing ideas.
- Part of the user-centered design approach which puts people first.
- Ideal for spanning boundaries of specialization.

References

Adlin, T., & Pruitt, J. (2010). *The essential persona lifecycle: Your guide to building and using personas*. Burlington: Morgan Kauffman.

Carroll, J. M. (2000). *Making use: Scenario-based design of human-computer interactions*. Cambridge: MIT Press.

Council of Canadian Academies. (2017). *Older Canadians on the move*. Ottawa: The Expert Panel on the Transportation Needs of an Aging Population, Council of Canadian Academies.

International Organization for Standardization–Technical Committee ISO/TC 159/SC 4 9241-210. (2010). *Ergonomics of human system interaction-Part 210: Human-centred design for interactive systems*. Geneva: International Standardization Organization.

Kulak, D., & Guiney, E. (2012). *Use cases: Requirements in context* (2nd ed.). New York: Addison-Wesley.

Levina, N., & Vaast, E. (2005). The emergence of boundary spanning competence in practice: Implications for implementation and use of information systems. *MIS Quarterly, 29*(2), 335–363.

Pruitt, J., & Grudin, J. (2003, June). Personas: Practice and theory. In *Proceedings of the 2003 conference on designing for user experiences* (pp. 1–15). New York: Association for Computing Machinery.

Sanders, B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *Co-design, 4*(1), 5–18.

Sy, D. (2007). Adapting usability investigations for agile user-centered design. *Journal of Usability Studies, 2*(3), 112–132.

Chapter 29
Cross-Cultural Adaptation of Existing Health Technologies

W. Ben Mortenson, Claudine Auger, Garth Roston Johnson, and Manon Guay

The Challenge

New health technologies (e.g., products, services, policies, interventions designed to help people maintain their independence) are usually created in a way that makes them specific to the culture in which they were developed. Cross-cultural adaptation of health technologies considers the "language, culture, and context in such a way that it is compatible with the [user]'s cultural patterns, meanings, and values" (Bernal, Jiménez-Chafey, & Domenech Rodríguez, 2009, p. 362). This chapter will

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Box 29.1 Examples of Cultural Adaptation Failures and Successes in Business

From the business world, there are many examples in which popular products (i.e., technologies) in one country were not implemented well into another. One cautionary example is the introduction of eBay into China. The company attempted to enter the Chinese marketplace using the same strategies they had successfully used in many other countries. In the end, however, they were unable to compete with what was, at the time, a smaller local company (i.e., Taobao, a subsidiary of Alibaba). Taobao is now one of the leading e-commerce companies worldwide (with more sales than eBay and Amazon combined).

Culturally congruent attributes of the online interface are the main reasons for Taobao's success, including elements such as commerce practices, gender specificity, and symbolism (SAOS, n.d.). In China, sellers as well as buyers want to have casual interactions to help develop a sense of trust. Unlike eBay, Taobao offered customers the opportunity to communicate via a synchronous chat application that facilitated negotiations between buyers and sellers. The platform includes navigation tabs for men and women, which are lacking on western e-commerce sites. The platform is themed in red and orange, which symbolize festivity and prosperity. The platform also appeals to a strong nationalist sentiment in China by referencing fictional characters from a renowned series of Kung Fu novels by Jin Yong. In these ways the website is uniquely suited to the culture of its intended users.

discuss some of the considerations that should be taken into account when applying solutions across different cultures.

The extent of cultural adaptation will likely depend on the type and complexity of the technology. For example, if someone is having trouble with gripping, the adapted pen they use might be successfully introduced with little modification into another culture that uses similar writing implements. For tasks that are more complex or exhibit greater cultural variation, more substantial changes are likely required.

Box 29.2 Hypothetical Example of the Cultural Adaptation of a Robot for Self-Feeding

If a North American company were to create a robot to assist people feeding themselves, this would likely require considerable culturally specific knowledge. For North Americans, the robot might use utensils, like forks, knives, and spoons. It might also need to understand when it was appropriate not to eat with utensils (e.g., hamburgers, pizza, and cookies are rarely consumed

(continued)

Box 29.2 (continued)

with a fork and knife). If the system were to try and mimic proper table manners, it might follow the advice of Emily Post (http://emilypost.com/advice/how-to-eat-soup/), but this approach may seem overly fastidious to many potential users who prefer eating in less formal settings. If the device were to be introduced into a country where chopsticks are the preferred way of eating, it would likely need considerable modification to enable it to use these utensils for a variety of dishes and also be sensitive to proper etiquette (e.g., not using the chopsticks individually like spears).

With other intelligent devices like robots, which could have language abilities and gestural or facial attributes, considerable cultural adaptation would likely be required. Similarly, with interventions that are language-based, there is considerable scope for cultural adaptation. We will address four key ideas to help address potential challenges during the cultural adaptation process:

1. Understanding four critical elements for cross-cultural adaptation.
2. Revisiting the business case.
3. Appreciating the bidirectional nature of cultural adaptation and technology development.
4. Developing an in-depth understanding of the context in which the technology will be used in the new culture.

Box 29.3 Cross-Cultural Adaptation of UK SmartAssist to the Canadian Context

The UK company ADL Smartcare offers an e-decision aid called SmartAssist for older adults and their caregivers. This decision aid (i.e., an evidence-based tool to help people make specific and deliberate choices among different healthcare options) allows self-selection of assistive technologies to promote independence. AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence) has supported the exploration of a cross-cultural adaptation on the part of SmartAssist relating to the activities that are completed in the bathroom (e.g., toileting, bathing, cutting toenails) to the Canadian context. Certain challenges were faced during the cross-cultural adaptation of this existing health technology. SmartAssist will be used as a touchstone in the four ideas that are offered.

Key Ideas

Key Idea 1: Cross-Cultural Technology Adaptation Requires Consideration of Four Critical Elements

Language (generic). While it is self-evident that a change of language requires necessary translation of words and phrases, it must also be remembered that changes of idiom are likely to be a key component of translation, i.e., automated translation software is unlikely to be adequate. When culturally adapting SmartAssist, it was noted that some English words in the UK version of SmartAssist were not commonly used in Canada. Examples include asking about a person's weight in stones (1 stone = 14 pounds) or using the word cistern for what would be described as a toilet tank in North America. Therefore, cultural equivalences needed to be identified.

Living and home culture (topic dependent). The national and/or regional culture may be seen as a definition of lifestyle and behavior. In the specific case of aging and independence, there are likely to be well-established cultural perspectives that may influence the acceptability and usage of the system. These are likely to be particularly important for toileting and feeding. For example, high-tech toilets in Japan have a variety of features that are not commonly found in other countries including bidet functions, heated seats, blow-drying, massage options, water jet adjustments, automatic lid opening, automatic flushing, wireless control panel, and environmental controls. Some are equipped to automatically create the sound of running water to cover the sound of bodily functions. Similarly, the geography and climate will have an influence on infrastructure and home design. For example, in terms of bathroom design specificity, SmartAssist in the UK needed to consider the potential presence of pipes around the toilet that might not accommodate some assistive technologies; however, such pipes rarely exist outside the walls around Canadian toilets. Also in the UK, grab bars need to be grounded, but that is not a requirement in North America.

Ethnic or religious influences. A number of personal care tasks may be influenced by ethnic or religious practices. These influences will not necessarily be country-specific and are likely to be present in a large number of countries where there is a wide variety of ethnic groups. Their accommodation must therefore become the norm. For example, Berry, Halpenny, Bosco, Bruyere, and Sanda (2015) stressed that decision aid users need to be able to see themselves using the tool. So when adapting a decision aid to a Spanish context, Spanish video clips were produced using bilingual Latino actors to play patients and physicians. Similarly, Ko, Reuland, Jolles, Clay, and Pignone (2014) adapted the content of a decision aid to take into consideration and integrate Latino sociocultural realities such as familism (i.e., the importance of family over individual interests), power distance, and machismo. Given that Canada is a bilingual country and to ensure access to all Canadians, SmartAssist needed to be adapted to Canadian English and translated into French Canadian, which represent distinct cultures.

Political and socioeconomic factors. There is a wide variation in political and economic cultures between countries and, indeed, between regions and states within any single country. These factors will have a profound influence on the method of funding ranging from completely self-funded to a totally state-funded system. This variation may also apply to the provision of health technologies and so influence the form of advice and information provided as well as the method of choice and supply. For example, in Canada, health technologies are funded differently (i.e., depending on the technology) in each province, so a developer that wants a device to be publically funded would need to consider the local funding policies carefully and identify appropriate price cut points. The UK is a pioneer in developing online decision algorithms for providing recommendations about assistive technologies to the general public; it is an innovative way of delivering advice to older adults and their caregivers. However, this approach may raise some resistance in Canada since this advice has been traditionally given by health professionals.

Key Idea 2: Developing a Strong Business Case to Ensure That a New Health Technology Can Be Sustainable When Introduced into a New Culture

It would likely be beneficial to revisit the business canvas in Chaps. 38, 42, 43 when considering the introduction of a health technology into a new cultural market, rather than applying it carte blanche to the new setting. This will help to identify potential changes in the value proposition (i.e., service, feature, or innovation that makes a product attractive to customers (e.g., price and efficiency or overall customer experience), infrastructure (e.g., key resources, key activities, supply chain), customers (e.g., mass market, niche market), and finances (e.g., cost structure [cost-driven vs value-driven] and revenue stream)). The American retail company Target's aborted launch in Canada likely represents a failure to reconsider a revised business canvas in this regard. The store encountered many supply issues that left shelves barren. Furthermore, the retail prices were higher than those offered in the USA, and there was little consideration for how Canadians preferred shopping in multiple stores as opposed to the American style of one-stop shopping (McMahon, 2017). Additionally, they underestimated the competitiveness of the Canadian marketplace. In the UK, the use of SmartAssist is often covered by local authorities that have a responsibility for social care although this is a potential business model in the Canadian market; SmartAssist in other countries may be more suitable as a self-paid service.

Key Idea 3: Understanding the Bidirectional Nature of Cultural Adaptation and Technology Development, i.e., the Transactional Potential

Sometimes when a technology is adapted with the involvement of members of the target culture, a novel technology may be developed. For example, in a study by Jull et al. (2015), community members preferred to use a paper-based decision aid as a talking guide rather than a self-reflective tool because they found face-to-face, in-person communication with a decision coach to be a better fit with their own cultural approach to problem-solving. Allowing the adaptation to be flexible likely leads to the creation of a potentially novel technology, which is better suited to the target culture and therefore more likely to be adopted. When adapting the language of SmartAssist that was fitting to the Canadian cultural context, literacy issues were identified and adjusted to reflect lower reader levels; these changes were reintroduced in the UK version of SmartAssist.

Key Idea 4: Develop a Detailed Understanding of the Context Within Which the Technology Will Be Used

Health and social care systems vary considerably from one country to the next. Language issues may further complicate matters. For example, in describing an intervention that was delivered by *district nurses* who are the most frequent kind of ambulatory nurse (i.e., a nurse who cares for people in settings other than hospitals) in France, the expression *district nurse* was translated into French as *infirmière à domicile* (home care nurse), which represents a different type of nurse in English (Coudeyre et al., 2014). This raised questions about how the intervention might be delivered in other countries or settings. Another example from our own research required cultural adaptation of a British online decision aid to help people identify suitable assistive technologies to meet their needs to a Canadian context. When considering the adaptation, not only were there language considerations for both French and English, but there were also important questions regarding the notable differences in assistive technology selection processes in each country and the range of products that were available. In Canada, some jurisdictions have limited public funding for products, and so users of assistive technology would choose devices based on what they were prepared to pay. While in other jurisdictions, a limited selection of products can be obtained using public funding with approval from an approved assessor. Both options would require radically different approaches to implement the system or indicate the need for the development of a revised system of prescription. For further information or client assistance, in the UK, occupational therapists are available over the telephone and in outpatient clinics to support older adults and their caregivers while they are navigating SmartAssist. However, these services are not offered in Canada. Importantly, cross-cultural adaptation challenges highlight the need to identify potential assistance proactively.

Product Innovation Pathway Model

We have populated Table 29.1 with concrete suggestions about how cultural adaptation can be integrated into each level of the product development pathway.

Supporting Resources
- Cultural adaptation of health communication materials

Translation is not enough
https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/translation-is-not-enough.pdf.

- Adapting community-based interventions:

  Adapting community interventions for different cultures and communities
  https://ctb.ku.edu/en/table-of-contents/analyze/choose-and-adapt-community-interventions/cultural-adaptation/main.

Key Messages
- Adequate cultural adaptation is crucial for the adoption of novel technologies into a new culture and will likely prevent costly mistakes.
- Four critical aspects to consider with cultural adaptation include language, living and home culture, ethnic or religious influences, and political and socioeconomic factors.
- Developing an understanding of the context of use and creating a detailed business canvas are essential for ensuring the sustainability of novel health technologies in a new culture.

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Table 29.1 Product Innovation Pathway (PIP) model

PIP model			Cross-cultural adaptation
PIP level	PIP description	Description	How this applies to cross-cultural adaptation of innovations
1	Concept	This is about generating ideas, collaborations, and initial plans that may lead to a useful product down the line. It is essentially about developing the vision and goals of a project.	• Exploration stage (what needs to be adapted, what is the complexity of the adaptation needed for the new context) (Chenel, Mortenson, Guay, Jutai, & Auger, 2018). • This should consider the structure, content, and complexity of the original technology (Cudd & De Witte, 2017). • If introduction of a technology into different cultures is expected, developers might consider ways to make the measure culturally neutral at the onset (e.g., avoiding use of slang or idioms with written materials). • Culture is just one aspect of a whole host of intersectional issues that likely need to be considered when developing new technologies. People are different from one another and such differences may be characterized by intersections of sex (biological), gender (cultural), age, disability, race (biological), and ethnicity (cultural). • Meaning-making, meaning of innovation. What technologies are currently used in that culture for that purpose? What previous technologies have not been successfully introduced? What explanations exist for those failures? Potential explanations could involve stigma associated with technology use (Mortenson & Miller, 2008). Problems identified in one culture may not be considered problems in another. For example, some cultures may emphasize independence, whereas others stress interdependence.
2	Planning	This turns ideas into formal proposals, plans, projects and initiatives with people, teams, partners, etc. The product is defined.	• Defining the methods for the cross-cultural adaptation: it is critical to identify the tasks, methods, and expertize needed to adapt each category of content (Cudd & De Witte, 2017). • This also involves considering who is introducing the innovation in the culture and how access to the technology in the new culture is enabled (e.g., Internet connection in rural areas). • A fundamental question for careful consideration: "Is the innovation needed in the new culture?" This is important because you can only adapt a product so far until it becomes apparent that it may not be the right solution. • Training might be another way to facilitate adoption (i.e., modifying the environment and culture of use, rather than changing the product). • Providing incentives—how would you encourage change in practice?. • It is also important to consider who is left behind (e.g., the shared economy in urban vs rural areas).

Table 29.1 (continued)

3	Development	The early ideas are refined, developed, and turned into products. Technologies might go through different steps of prototyping. Policies and service models need to be refined.	• Adaptation of the innovation (e.g., adapting the language and the way activities are performed in the new culture, choosing the right format to display the content of the messages). • For written material, the original text needs to be extracted and put into a format that can be manipulated by experts who are involved in the adaptation process. • During this process, it is critical to remember: “You will never be an insider. Don’t assume. Continue to check in.”
4	Testing	Products are tried out and evaluated in real-world situations. This will provide the evidence needed to go to the next level or indeed go back and develop the product further. This may be some kind of trial, pilot, or demonstration.	• Pilot testing with potential users (Chenel et al., 2018). This involves field testing the adapted technology with potential end users to explore not just its effectiveness but also its acceptability and usability.
5	Implementation	The final phase is about the practical steps needed to get the product adopted into the real world.	• Implementing the product in the new culture. This requires evaluating performance of the technology with real users as it is integrated into practice or into the workflow of the new environment. This could involve effectiveness trials that examine real-world outcomes in messy real-world settings. Cost-effectiveness is also a critical issue for consideration.

References

Bernal, G., Jiménez-Chafey, M. I., & Domenech Rodríguez, M. M. (2009). Cultural adaptation of treatments: A resource for considering culture in evidence-based practice. *Professional Psychology: Research and Practice, 40*(4), 361–368. https://doi.org/10.1037/a0016401

Berry, D. L., Halpenny, B., Bosco, J. L. F., Bruyere, J., & Sanda, M. G. (2015). Usability evaluation and adaptation of the e-health Personal Patient Profile-Prostate decision aid for Spanish-speaking Latino men. *BMC Medical Informatics and Decision Making, 15*(1), 56. https://doi.org/10.1186/s12911-015-0180-4

Chenel, V., Mortenson, W., Guay, M., Jutai, J., & Auger, C. (2018). Cultural adaptation and validation of patient decision aids: A scoping review. *Patient Preference and Adherence, 12*, 321–332. https://doi.org/10.2147/PPA.S151833

Coudeyre, E., Eschalier, B., Descamps, S., Claeys, A., Boisgard, S., Noirfalize, C., & Gerbaud, L. (2014). Transcultural validation of the Risk Assessment and Predictor Tool (RAPT) to predict discharge outcomes after total hip replacement. *Annals of Physical and Rehabilitation Medicine, 57*(3), 169–184. https://doi.org/10.1016/j.rehab.2014.02.002

Cudd, P., & De Witte, L. (2017). *Harnessing the power of technology to improve lives*. Amsterdam: IOS Press.

Jull, J., Giles, A., Minwaashin Lodge, The Aboriginal Women's Support Centre, Boyer, Y., & Stacey, D. (2015). Cultural adaptation of a shared decision making tool with Aboriginal women: a qualitative study. *BMC Medical Informatics and Decision Making, 15*, 1. https://doi.org/10.1186/s12911-015-0129-7

Ko, L. K., Reuland, D., Jolles, M., Clay, R., & Pignone, M. (2014). Cultural and linguistic adaptation of a multimedia colorectal cancer screening decision aid for Spanish-speaking Latinos. *Journal of Health Communication, 19*(2), 192–209. https://doi.org/10.1080/10810730.2013.811325

McMahon, T. (2017, June). Missing the mark: Five reasons why Target failed in Canada. *The Globe and Mail*. https://www.theglobeandmail.com/report-on-business/missing-the-mark-5-reasons-why-target-failed-in-canad/article22459819/.

Mortenson, W. B., & Miller, W. C. (2008). The wheelchair procurement process: Perspectives of clients and prescribers. *Canadian Journal of Occupational Therapy, 75*(3), 167–175. https://doi.org/10.1177/000841740807500308

SAOS (n.d.). Why Taobao succeed in China unlike EBay. https://www.saos.biz/procurement-in-china/why-taobao-succeeds-in-china-unlike-ebay/.

Chapter 30
Iterative Prototyping and Co-design

Daniel Southwick, Gabby Resch, and Matt Ratto

The Challenge

Within the disciplinary contexts of engineering and human-computer interaction, participatory, user-centered, and co-design methods have long been used to facilitate collaboration between makers and users of technological systems. While approaches such as these are a positive move in the direction of engaged research, our experience in developing and carrying out user-centered design-based projects leads us to believe that one-off engagements among researchers, designers, and stakeholders are insufficient, especially when issues of equality and social justice are at stake. This chapter describes our experiences attempting to facilitate ongoing and interactive relations between makers and users. Specifically, we highlight how the steps of *rapid sketching* and *prototyping* in a design process are ideal sites to foster persistent collaborative engagement among researchers, designers, and stakeholders. Our primary goal in encouraging ongoing multifaceted collaboration is to support critical reflection on the social implications of real-world solutions at various steps in order to support more meaningful, just, and equitable outcomes. The key ideas outlined in this chapter are:

- Determining what counts as participation in designing a real-world intervention is crucial.

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- Identifying, taking into account, and learning from the underlying social context support the successful deployment of products, services, and interventions.
- Encouraging a culture of responsibility that extends throughout prolonged design and product maturation cycles can promote longevity.

Key Ideas

Determining What Counts as Participation

When diverse groups of researchers, designers, and stakeholders come together to ideate, there is often a point at which their respective contributions are separated. Specifically, designers and developers take on the heavy lifting of sketching and prototyping, researchers probe with guiding questions, and community participants and/or stakeholders provide insights, content, and feedback. However, once community stakeholders, who are not involved in shaping the research questions or doing technical and conceptual design, have provided their content, insight, and feedback, they are frequently excluded from the design process. These stakeholders are then required to patiently await its final steps. In fact, research in various fields has demonstrated the value of including stakeholders throughout all steps of the design process (Bayley & French, 2008; Le Dantec & DiSalvo, 2013). The sketching and prototyping steps, we claim, are fertile territory for seeding persistent collaboration among these diverse groups. From this context these questions arise: How are the contributions of these various stakeholder groups counted as equal participation? How does their feedback get integrated equally? How can we ensure that they have an active and participatory role throughout the iterative design process and are not relegated to providing initial seed ideas or generating content?

In this case study of a project conducted by members of our lab—the Critical Making Lab at the University of Toronto—these issues were brought to the fore.

Box 30.1 Blind Tennis
In 2014, our lab was approached by members of a Toronto-based blind tennis club with a proposal to build an improved blind tennis ball (Ratto, Record, Coons, & Julien, 2014). Unhappy with slow, cumbersome play resulting from the conventional use of a large foam ball containing a mechanical noisemaker, the blind tennis club wanted to develop a new ball prototype that would allow its members to play something more closely resembling sighted tennis. In a subsequent workshop, the tennis players and members of our lab discussed the problem and experimented with possible solutions, including embedding an accelerometer in the ball and mapping it to a high-pitched audio output. During this experimental prototyping stage, however, an issue emerged regarding how work would be divided. The members of the blind tennis club were actively engaged during the more open-ended content discussion phase

(continued)

Box 30.1 (continued)
of the workshop, primarily through supporting sketching and paper prototyping by sighted members of our lab. However, once the work moved off paper and into direct work with middle-fidelity prototypes, the participation of the members of the blind tennis club was dramatically reduced. This division of work stemmed in large part from the fact that the mostly screen-based tools used to prototype were functionally dependent upon the user having vision.

We felt there was more to be learned from the continuing participation in the process by the blind tennis players. Therefore, we took a step back from the production of the actual prototype tennis ball and redirected our attention toward making tools that would address the imbalance between blind and sighted participants. In the end, our lab created a tactical circuit guide that used 3D printed circuit templates to facilitate the placement of components and a talking multimeter to support the selection of components by blind participants. By accommodating the blind tennis players in this way, we were able to facilitate ongoing development through additional workshops that allowed for stakeholders to continue their participation.

The efforts of the Critical Making Lab, it should be noted, are organized around the making of material objects. However, the production of these devices is not our ultimate goal. Rather, through the sharing experience of *making* and an ongoing critical analysis of materials, designs, and outcomes, our lab seeks to engage with pragmatic and theoretical issues around information and information technology.

As the case above indicates, involving community stakeholders in various steps of design can induce more empathetic solutions. Creating opportunities for all groups to participate and to have their participation valued equally is crucial to ensuring that all stakeholders remain engaged. Incorporating this ethos into the earliest phases of sketching and prototyping will assure that community stakeholder contributions are not reduced to mere seed content or just feedback.

Identifying, Taking into Account, and Learning from the Underlying Social Context

Researchers and designers often fail to fully account for complex social and contextual variables that arise when designs move out of a lab setting or controlled design environment and are instantiated in real-world contexts. Similarly, community stakeholders are often unable to readily identify or describe, in full breadth, underlying problems that may contribute to the lack of adoption, use, and success. Prototyping is an ideal stage for real-world contextual variables to be surfaced, discussed, and accounted for or resolved. In the case study below, we provide an example of an ongoing project run out of our lab that highlights difficulties that arise, as well as benefits that occur, when we design with social context as a foremost concern.

Box 30.2 3D PrintAbility
Nia Technologies, a Toronto-based nonprofit social enterprise that is developing and deploying 3D printed prosthetics solutions for lower- and middle-income countries (LMICs), is an offshoot of a research project undertaken by our lab in 2013 (Ratto, 2018). The goal of the project, as it was originally conceived, was to develop a workflow using 3D printing and scanning technologies that would lessen the production time of prosthetics and orthotics devices while also reducing the amount of time patients and guardians spend in clinics or hospitals during the fitting process. These goals were established as a result of prolonged discussions with prosthetics and orthotics (P & O) clinicians in both the LMICs and higher-income countries. These discussions centered on problems faced by patients and P & O professionals in LMICs' contexts. Following initial consultations, researchers from our lab engaged in a thorough review of contemporary technological innovations being proposed for LMICs' contexts. As a result of this review, we became aware of a potential issue: clinicians rarely (if at all) discussed power dynamics associated with technological solutions created for LMICs by designers in the higher-income countries. In subsequent discussions with clinicians, we brought this issue up. This led to the project's goal statement being revised such that any solution developed had to ensure that design work for the P & O devices would be done in ways that supported the growth and preservation of local expertise. Based upon this revised goal, an initial prototype was developed and deployed that successfully addressed the underlying problems described by clinicians and also illuminated other potential social issues that had not been communicated initially.

Accounting for social context rarely happens at the outset. Detailed problem statements that are typically generated at the start of a project can miss broad social concerns that may ultimately affect adoption and use. Frequently, social context is assumed, based on current beliefs or experiences, and the potential transformative impacts of the technical innovation are not addressed. We believe that the way to address this issue is to continually revise problem statements as the stakeholders encounter prototypes of the technological innovation in increasingly realistic contexts. In the case described in Box 30.2, for example, one problem that emerged from the initial discussions had to do with the fact that design and fabrication of prosthetic and orthotic devices can take a significant amount of time. While this was a valid concern, some of the solutions proposed to solve this issue could have done more harm than good. One proposed solution was to have clinical staff in the LMICs scan patients and send the results to higher-income countries' CAD/CAM experts who would be responsible for producing 3D printable models. While this solution would be adequate from a technical and cost standpoint, the off-loading of expert labor would have led to a diminishment of expertise of local staff. As noted above, we revised the initial problem statement to include reference to local expertise and an overt goal of supporting and extending the skill and capacity of LMICs' clinical staff. However, accounting for context requires more than adapting the instrumental logic that guides a successful design. By attempting to understand various contexts of adoption and use, a sense of responsibility in the researchers, designers, and stakeholders who participate in the project can be cultivated.

Encouraging a Culture of Responsibility

The successful development and deployment of technological interventions require that researchers, designers, and stakeholders each develop a sense of responsibility both for a design and for its successful implementation in a real-world context. Each of these groups, however, has their own requirements, obligations, values, and needs that can make prolonged design and product maturation cycles a potential site of conflict. In the case study, we discuss a workshop developed by our lab that attempts to incorporate *responsibility* as a key facet of the prototyping process.

Box 30.3 The Design Dash

As part of lab's ongoing design collaboration with AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence), we have developed and run a number of workshops that teach sketching and prototyping approaches that encourage critical reflection at various steps of a design cycle. There is one caveat worth mentioning: sketching and prototyping are not the same thing; however, we often have to blur the two when the timer is on.

Sketching diverse personae and interactions is an important part of reflexive prototype development, but prototyping software interfaces or hardware devices is required to place these personas and interactions into a realistic context. *The Design Dash* is a workshop that was originally developed for AGE-WELL's Summer Institute. In this workshop, participants are provided with conceptual and material resources to produce various rudimentary prototypes of technological interventions. These prototypes are eventually incorporated into group pitches. The Design Dash uses a cyclical prototyping model that begins with participants developing problem and needs statements. Following this, participants develop speculative scenarios in order to conceptualize designs, as well as to refine their problem and needs statements. Finally, participants sketch ten distinct possible solutions that respond directly to their problem statements.

Each of these steps is timed with participants being constrained by the 10-min window in which they must work. We further constrain the process by requiring that groups come up with at least one new software application idea, one new service idea, one new hardware idea, and one new policy idea. The purpose of these constraints is to prevent groups from dwelling on individual solutions.

Furthermore, we insist that groups do not propose a social media application based on any popular existing platform. After participants have completed each stage, they are instructed to commence from the beginning and redo the entire process. With each successive pass, participants typically focus on a specific idea and are encouraged to begin cultivating a sense of responsibility for it.

Developing a cohesive needs statement is at the foundation of collaborative design. Being able to modify a needs statement through the kind of cyclical design process described above can ensure that stakeholders feel engaged in the iterative improvement of a product or service. While there is room for speculative scenarios toward the end of a design dash (or similar prototyping process), cultivating a sense of responsibility requires that stakeholders can envision a real-world context or manifestation for the product or service they are developing. *Responsibility* does not simply entail reaching some predefined benchmark for success. When working with vulnerable populations, for example, it is critical to engage probing questions about ethics, social impact, etc. and not just leave these subjects to ethicists or humanists (who may or may not be involved in the process). Being responsible requires engaging with complex ethical and social questions throughout every stage of the design process. It requires that each person involved weigh-in on these issues.

Importantly, being able to see the forest for the trees helps stakeholders foster the kind of responsibility that we're talking about. This applies regardless of whether the design cycle is short or long, simple or complex. Developing speculative scenarios through sketching and prototyping helps ensure that stakeholders do not lose sight of potential issues that can come up when their intervention manifests in a real-world context.

Iterative Prototyping and Co-design and the Product Innovation Pathway Model

Rapid sketching and prototyping would generally be considered as part of the third and fourth stage of the Production Innovation Pathway (PIP) model. Yet, as we have discussed, rapid low-fidelity sketching and prototyping that addresses issues of equality and social justice requires co-design to occur at virtually all steps of the model. Some of the key activities and their corresponding steps are identified in Table 30.1.

Finding Support
Throughout the sketching and prototyping process, we strongly advocate for the construction and modification of problem and needs statements. These tools are becoming well known in socially engaged and values-driven design. Our practice typically involves frequent reassessment, adaptation, and modification of problem and needs statements based on the discovery of new conditions that might impact the real-world deployment of a design output.

Our approach to prototyping has been strongly informed by sketching and prototyping methods that have been described by Buxton (2010) and Greenberg, Carpendale, Marquardt, and Buxton (2011). A number of the techniques we use in the *design dash* have been modified from ones proposed in their works. Our approach diverges somewhat in that we strongly encourage seeding moments for critical reflection throughout the entire design process—especially self-reflection

Table 30.1 Product Innovation Pathway (PIP) model—prototyping and co-design

PIP level	PIP description	Key activities
1	Innovative ideas	Identify and develop iterative processes for deriving problem and need statements that adequately address social context
2	Planning	Discuss what counts as participation and how the contributions of the various researchers, designers, and stakeholders will be used. Plan for maintaining engagement by all parties throughout the duration of the design cycle
3	Development	Produce sketches as well as low-, middle-, and high-fidelity prototypes. Use these as a means of fostering reflexive discussion among researchers, designers, and stakeholders; based upon feedback, further refine problem and needs statements
4	Testing in real-world environment	After the technological innovation has been developed, discuss if/what new problems have emerged; potentially begin sketching and prototyping toward adaptations or modifications
5	Outcomes and impact	Encourage a culture of responsibility; researchers, designers, and stakeholders should be ready for additional new and unforeseen problems caused by the technological intervention

with respect to one's own values and epistemic commitments. This design stance draws heavily on Agre (1997), Ratto (2011), and Sengers, Boehner, David, and Kaye (2005), all of which discuss the importance of prototyping, iterative co-design, and reflexivity in great detail. Equally, we have found the emerging fields of *value-sensitive design* (Friedman, Hendry, & Borning, 2017) and *values in design* (Flanagan, Howe, & Nissenbaum, 2008) to offer valuable areas of departure for sustained engagements between design and issues of social justice, equality, and ethics.

Finally, when we talk of cultivating an ongoing sense of responsibility, with respect both to the success of a product, service, or intervention and to the communities or stakeholders affected by it, we draw on de la Bellacasa's (2011) notion of *matters of care*. This is a speculative approach that invites designers and stakeholders to think about what could be different. More than anything else, it entails an attention to concerns that are often neglected in technology design.

Key Messages

Prototyping is often an ideal stage for fostering long-term, multifaceted engagement between researchers, designers, and stakeholders. In order to facilitate polyvocal engagement at and beyond this stage, it is advised that:

- Insights generated by community stakeholders must be treated as equally valuable (beyond simply asking them to seed the design process with content).
- Considering wide-ranging social contexts and use scenarios is a crucial part of ensuring that unforeseen problems are surfaced early on.
- Long-term care requires continuous iterative engagement, as well as fostering a sense of responsibility among all researchers, designers, and stakeholders.

References

Agre, P. (1997). Toward a critical technical practice: Lessons learned in trying to reform AI. In G. Bowker, L. Gasser, L. Star, & B. Turner (Eds.), *Bridging the great divide: Social science, technical systems, and cooperative work* (pp. 131–158). Hillsdale: Erlbaum.

Bayley, C., & French, S. (2008). Designing a participatory process for stakeholder involvement in a societal decision. *Group Decision and Negotiation, 17*(3), 195–210.

Buxton, B. (2010). *Sketching user experiences: Getting the design right and the right design*. Burlington: Morgan Kaufmann.

De la Bellacasa, M. P. (2011). Matters of care in technoscience: Assembling neglected things. *Social Studies of Science, 41*(1), 85–106.

Flanagan, M., Howe, D. C., & Nissenbaum, H. (2008). Embodying values in technology: Theory and practice. In J. van den Hoven & J. Weckert (Eds.), *Information technology and moral philosophy* (pp. 322–353). Cambridge: Cambridge University Press.

Friedman, B., Hendry, D. G., & Borning, A. (2017). A survey of value sensitive design methods. *Foundations and Trends® in Human–Computer Interaction, 11*(2), 63–125.

Greenberg, S., Carpendale, S., Marquardt, N., & Buxton, B. (2011). *Sketching user experiences: The workbook*. Burlington: Morgan Kaufmann.

Le Dantec, C. A. L., & DiSalvo, C. (2013). Infrastructuring and the formation of publics in participatory design. *Social Studies of Science, 43*(2), 241–264.

Ratto, M. (2011). Critical making: Conceptual and material studies in technology and social life. *The Information Society, 27*(4), 252–260.

Ratto, M. (2018). Piloting 3D printing technology to increase access to prosthetic devices. In E. James & A. Taylor (Eds.), *Managing humanitarian innovation: The cutting edge of aid* (pp. 177–182). Rugby: Practical Action Publishing. https://doi.org/10.3362/9781780449531.022

Ratto, M., Record, I., Coons, G., & Julien, M. (2014, September 15). Blind tennis: Extreme users and participatory design. In H. Winschiers-Theophilus (Chair) & Vincenzo D'Andrea (Chair), *PDC '14 proceedings of the 13th participatory design conference: Short papers, industry cases, workshop descriptions, doctoral consortium papers, and keynote abstracts*, Windhoek, Namibia (Vol. 2, pp. 41–44). https://doi.org/10.1145/2662155.2662199.

Sengers, P., Boehner, K., David, S., & Kaye, J. J. (2005). Reflective design. In *Proceedings of the 4th decennial conference on critical computing: Between sense and sensibility* (pp. 49–58). New York: Association for Computing Machinery.

Chapter 31
Case Study: Nia Technologies—Validating Your Solutions

Matt Ratto, Daniel Southwick, and Gabby Resch

The Challenge

The current method for making a below-the-knee prosthetic device in lower- and middle-income countries (LMICs) is a manual process of plaster casting, rectification, and thermoplastic molding. Using this method, it takes approximately 40 h of both manual labor and waiting time to produce a single prosthetic device. *3D PrintAbility* is a 3D scanning, design, and printing toolchain developed by Nia Technologies (Toronto, Ontario) that seeks to reduce the amount of time it takes to produce a prosthetic device. This reduction of time allows clinics in the LMICs to increase the number of patients they serve without requiring additional labor resources. The main goal of this intervention is to address the long-standing unmet need for prosthetics in the LMICs (World Health Organization, 2011). While other projects have sought to incorporate the use of digital fabrication technologies into the production of prosthetics in LMICs, what makes 3D PrintAbility unique is its focus on combining traditional orthopedic expertise and skills in manual production with these technologies.

It would be easy to characterize the development of the 3D PrintAbility toolchain as a technical intervention to a social problem, but doing so would obfuscate much of the work associated with the project. Initial work done in the

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A. Sixsmith et al. (eds.), *Knowledge, Innovation, and Impact: A Guide for the Engaged Health Researcher*, International Perspectives on Social Policy, Administration, and Practice, https://doi.org/10.1007/978-3-030-34390-3_31

Critical Making Lab at the University of Toronto highlighted the complex feelings held by prosthetists regarding the use of new technologies like 3D printing in their professional practice. After speaking with trained prosthetists in Canada, the United States, Cambodia, Tanzania, and Uganda it became apparent that there was a long-standing tension regarding how their craft-based expertise had been characterized as easily replaceable and capable of being automated by technological processes. The overall effect of this was that many of the prosthetists were wary of engaging with the project. They perceived 3D printing, and by extension 3D PrintAbility, as simply another attempt to devalue their expertise and their labor. At the same time, many of the prosthetists acknowledged a need to engage with 3D printing as they saw the adoption of technology within the profession as inevitable. As a consequence, they felt a need to assert their professional perspectives. The success of 3D PrintAbility as an intervention, then, needs to be measured in technical terms. For example, can 3D PrintAbility produce a high-quality socket and how successfully can 3D PrintAbility navigate these professional tensions? Failure to adequately do both would have long-term implications for the technology's adoption.

Initial Ideas and Priorities

The initial proposal for 3D PrintAbility took advantage of the ease of movement of digital scans and models available over the Internet. A toolchain was imagined in which the expertise and the labor of LMICs' prosthetists would be used to *digitally intervene* and to provide service to patients in LMICs. The workflow of such a system would involve technicians from the LMICs 3D scanning patients and then sending these scans over the Internet to prosthetists in locations such as Canada. The prosthetists would then use computer-aided design (CAD) tailored for prosthetic work to modify the scan data to produce a 3D model of a prosthetic socket. After completing the socket, the prosthetists would send the socket data back to the technicians in the LMICs for printing and fitting onto patients.

While such a solution is attractive from a technical perspective, as it would require limited developmental work and could be easily deployed, this toolchain was ultimately rejected as it was deeply problematic when viewed through the lens of global relations. The reality of such a toolchain is that it creates a division in which LMICs workers carry out the manual labor, while any intellectual expert work is done by professionals in the higher-income countries. Not only would this reify existing power hierarchies between higher-income countries and LMICs, but it would run the risk of diminishing certain kinds of expertise in the LMICs in favor of nonlocal expertise.

In an attempt to remedy, or avoid, these potential development pitfalls, priority was placed on ensuring any solution from higher-income countries: (1) fit into the existing aid efforts and establishment of sustainable health systems in the LMICs and (2) enhance, rather than replace, local capacities and expertise.

Iterative Development

The toolchain that was developed for 3D PrintAbility allowed prosthetists in the LMICs to scan the limb of a patient, then digitally rectify the scan data, and then print and fit the resulting prosthetic device. This process took approximately 24 h of combined labor and waiting time.

Following this development period, which took around 12 months, Nia Technologies undertook a large-scale clinical evaluation of the 3D PrintAbility toolchain. After completing the field testing phase of the evaluation, over 200 patients at four different clinical sites in three low-income locations were fitted for prosthetic devices over the course of a 2 year period (Ratto et al., 2017). The goal of the evaluation, as was initially conceived, was to be able to make statistically significant claims about the durability, fit, accuracy, and overall use of 3D printed prosthetic devices. From a technical perspective this data was vital, as it allowed Nia Technologies to *prove* the efficiency of the innovation in a way that was recognized by decision-makers in both governmental and medical contexts. An additional and unexpected benefit to the evaluation was that it allowed Nia Technologies to demonstrate its commitment to developing an innovation that actively fostered local expertise among clinicians and other stakeholders. This greatly strengthened key relationships and played a vital role in ensuring a successful iterative design process.

Commercialization

The business model developed by Nia Technologies to commercialize the 3D PrintAbility toolchain has sought to diversify the organization's revenue streams such that they were not dependent on grant and philanthropic funding. Using a dual market strategy, Nia Technologies has created a balance between LMICs' and higher-income countries' revenue streams (i.e., the 3D PrintAbility toolchain is sold in both LMICs' and higher-income countries' markets). The key and inherent challenge to this approach is finding contexts in the higher-income countries that resemble, or have similar needs, to that of higher-income countries. Targeted markets are being developed by working directly with caregivers in local hospitals. Specifically, a clinical trial is ongoing with St. John's Rehab at Sunnybrook Hospital, in Toronto (Ontario), where the accelerated time to fitting is believed to result in better outcomes for diabetic patients. In this case, accelerating time to the start of rehabilitation and increasing mobility is predicted to reduce morbidity and other negative outcomes.

Outcomes and Impact

Nia Technologies continue to expand its reach and the number of its clinical sites. Recently, an additional installation of equipment and an upgrading of hardware and software added new capacity to CoRSU hospital in Uganda. A site in Saudi Arabia is currently being started, and new installations are planned in Tanzania and Kenya for 2019. The success of 3D printability is directly connected to its focus on serving not just the needs of patients, but the professional needs of the clinical workers as well. Doing so requires deep attention and an understanding of how the related professions function, but also a desire to engage directly with professionals in their own processes of ongoing development. This requires connecting to clinicians in professional venues including their workplaces, training centers, and conferences, as well as staying sensitive to the professional changes adoption requires. Typical human-centered design techniques often end with the establishment of technical requirements. In the case of Nia Technologies an ongoing, iterative, and reflexive process of technological development that engages with users has resulted in more sustainable outcomes. Such approaches blend social analysis and technical development and are particularly suited for critical social problems (Ratto, 2016).

Key Messages

- Successful adoption of disruptive technologies in healthcare is supported by a deep engagement with the potential organizational and professional ramifications of changing clinical practice.
- Clinical professionals are often ambivalent about the changes brought by new technologies. Overcoming this requires commitment on the part of the providers towards validating their concerns and supporting internal decision-making.
- For projects that engage the LMICs, being aware and actively working against unequal power dynamics is an important precursor for sustainable success.

Project Details and Team The development of 3D PrintAbility was made possible due to funding from: cbm Canada; Grand Challenges Canada; Autodesk foundation; Google.org; Stronger Philanthropy; and the Jericho Foundation. The success of the project was made possible as the result the support of the clinical partners: CCBRT (Community Based Rehabilitation in Tanzania); Comprehensive Rehabilitation Services Uganda (CoRSU); Cambodian School of Prosthetics and Orthotics (CSPO); and the Tanzania Training Centre for Orthopaedic Technologists (TATCOT).

References

Ratto, M. (2016). Making at the end of nature. *ACM Interactions, 23*(5), 26–35.

Ratto, M., Qua Hiansen, J., Kaweesa, M., Taremwa, J., Heang, T., Kheng, S., … Evans, J. (2017). An international multi-center clinical study: Gauging patient experience with digitally designing, 3D trans-tibial prosthetic devices compared to manually produced prosthetic devices. In E. Lemaire (Chair), *International Society for Prosthetics and Orthotics World Congress 2017 abstract book* (paper no. 447, p. 189), Capetown, South Africa. https://cdn.ymaws.com/www.ispoint.org/resource/resmgr/4_EXCHANGE/ISPO-2017-Abstract_Book_FINA.pdf.

World Health Organization. (2011). *Joint position paper on the provision of mobility devices in less-resourced settings*. Geneva: World Health Organization.

Chapter 32
Learning Activity: The Design Dash—Bringing Your Abstract Ideas to Life

Gabby Resch, Daniel Southwick, and Matt Ratto

The Challenge

There is a common tendency to move rapidly toward physical manifestations of design ideas once they have been roughly sketched. This tendency has become widespread with the growing availability of digital fabrication technologies like 3D printing. While the desire to move into the realm of the concrete and material is understandable, as it stems from wanting to get solutions into the hands of users who will be impacted by them, doing so can hinder the ability to reflect upon the social and contextual implications of a proposed intervention. In this learning activity, we will provide a short walkthrough of a low-fidelity, paper-based method for iterative prototyping that we call *The Design Dash*. The goal of a *Design Dash* is to allow collaborative teams to reflect critically upon the various impacts their solution might have on its intended user population. In doing so, this learning activity can help researchers move from an abstract idea to a real-world intervention that accounts for both the underlying functional needs and the larger social context in which it will be deployed.

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Fig. 32.1 Problem statement worksheet

Problem Statement

Observation:

Population:

Problem:

Outcome:

Fig. 32.2 Need statement worksheet

Need Statement

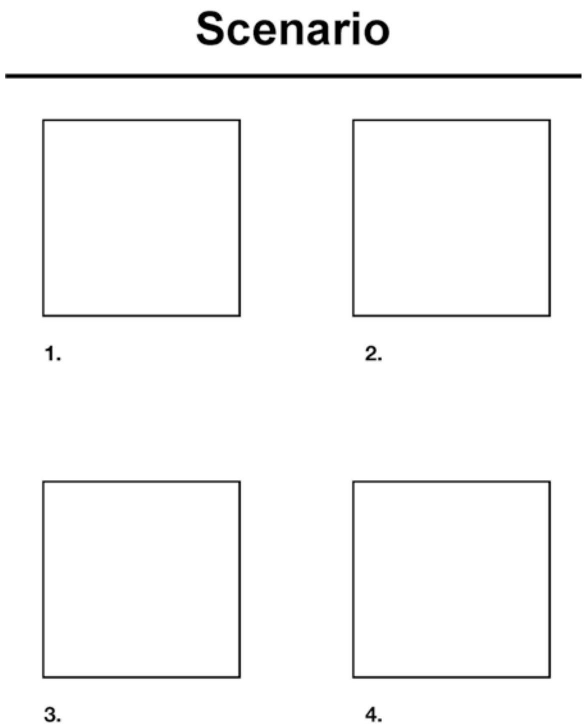
Need Statement One:

Need Statement Two:

Need Statement Three:

The Design Dash

The Design Dash is broken into six parts. Before beginning this activity, some materials need to be gathered. Figures 32.1, 32.2, 32.3, 32.4, and 32.5 are template worksheets. At least two copies of each, per group, will be needed.


Scenario

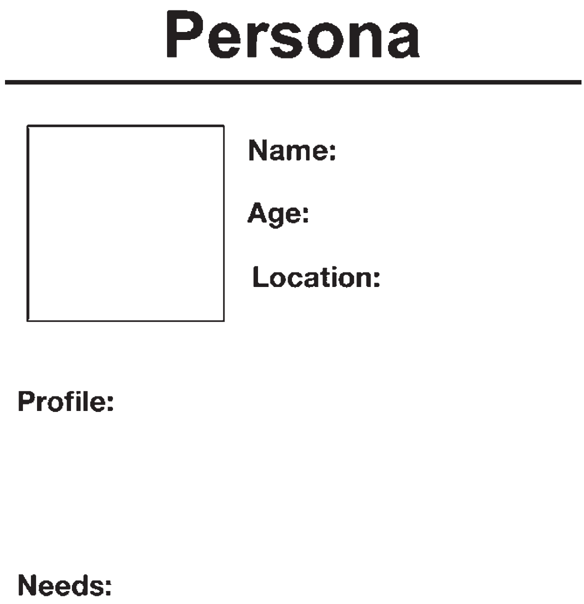
1.

2.

3.

4.

Fig. 32.3 Scenario worksheet


Persona

Name:

Age:

Location:

Profile:

Needs:

Fig. 32.4 Persona worksheet

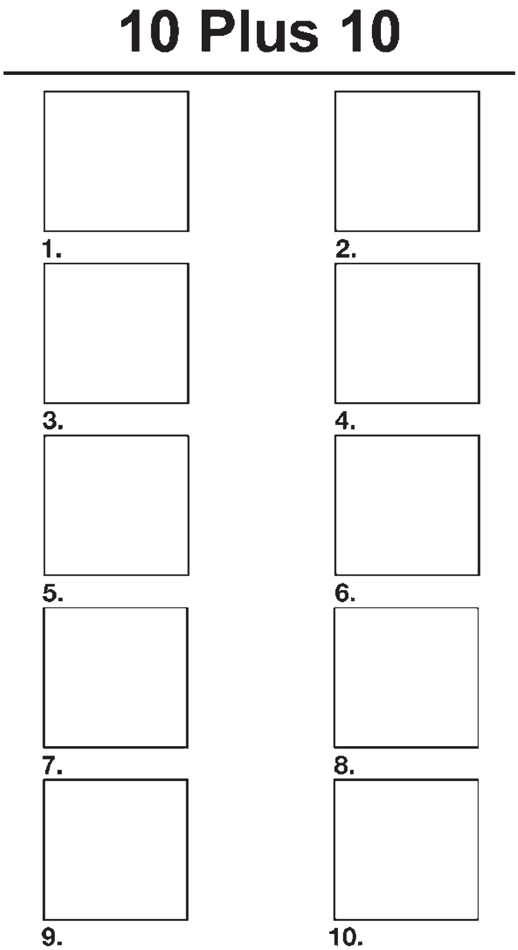


Fig. 32.5 10 plus 10 worksheet

Alternatively, blank pages can be used, but the headings and the overall structure of these pages should match the worksheet outlines. *The Design Dash* is a timed activity, so a timer or stopwatch will also be required. Each step has an approximate duration of 10 min. After each 10-min step has elapsed, 5 min should be allotted toward discussing and reviewing each of the previous steps. These tight time constraints are intended to prevent individuals and groups from dwelling too long on specific concepts.

Step 1: Problem Statements

First, you need to figure out the problem you are trying to address! There are multiple steps to this:

- **Observation**: Using qualitative, ethnomethodological techniques, observe and figure out the space you're working in. What do you see? What do you hear? Who is present? Observation helps you learn about your problem space, especially how care is already provided. Pay attention to both sites and people, and try not to produce too complicated a reflection.
- **Population**: Who are you trying to address the problem with or for? Who are your partners? Define your target population, not a generic user or wide category of users.
- **Problem**: This is the issue you're trying to solve. It emerges from your observations. Review what current interventions are like, and consider their shortcomings.
- **Outcome**: This is both your value proposition and the metric you will use to measure the success of your intervention. It is not your proposed design solution.

All statements should be concise, comprised of only one or two sentences. It should be noted that a problem statement can lead to multiple need statements!

Step 2: Need Statements

A need statement presents facts and evidence to support the need for the new project, program, device, or related intervention that you are proposing. Through writing a need statement, you will have an opportunity to divorce yourself from thinking about specific solutions. In fact, a good need statement should totally avoid mentioning a proposed solution!

Begin the process of translating what has been learned through problem statements into needs. Each problem must be reduced to a simple, causal factor that results in an undesirable outcome that can be addressed. Next, evaluate what change in outcome or practice the problem calls for, and determine how this can be measured. Finally, capture the essence of the need in a one-sentence statement that includes the problem, population, and desired outcome (if it is not obvious). How are you going to deliver a better outcome? Remember, this is not a space to define your solution!

Step 3: Persona

There is a tendency to create products or experiences for a general category of users, but this is something we strive to get away from. Personality can manifest itself in an interface through visual design, copy, and interactions. Creating unique design personas facilitates this, as personas color in the needs of the intended user. As you're working out a single concrete design persona from a more generic one, you may, in fact, create a funnel of attrition to identify additional target users.

Step 4: Scenario

This step is where you will first imagine a prototype within a specific practice or scenario of use. Scenarios describe how needs can be met by bringing design personas into conversation with need statements. They should be framed by narratives that can be illustrated in single boxes. In effect, a scenario is a story, and its narrative arc outlines when an intervention might occur. This is the step when you can actually talk about proposed solutions—but don't get too specific yet! The process of constructing a scenario should help you address multiple needs, including ones that you may not have considered earlier. It should be noted that, while scenarios are often intended to be fictional and speculative, you must remember that you are ultimately designing for actual people.

Step 5: 10 Plus 10

The 10 plus 10 design method, which we have adapted from *Sketching User Experiences: The Workbook* by Greenberg et al. (2011), will help you imagine various alternatives to original solutions that have been envisioned up to this point. To begin, you will need to revisit your problem and need statements as you will need to address how your sketches and prototypes reconcile with them throughout this process. Next, you will spend 10 min generating ten (or more but start with ten) rudimentary design concepts that could address your need statements. In doing so, you'll sketch out a simple iconic stub of your concepts and write very brief sentences or descriptive terms framing them. This process should be rapid and simple. Detailed sketches should be abstained from. We typically ask participants to imagine two speculative *moonshot* ideas.

Step 6: 10 Plus 10 (Redux)

Once you have ten simple ideas, you will review and discard until you are left with the two most promising ones. (If absolutely necessary, you can always cycle back to step 1 and generate new ideas!) One tactic that we often use is to mandate that groups must choose both a technology and a service. Once this has been done, produce ten variations of these one or two ideas, or focus on fleshing out ten details that alter your best idea's functionality. These may be aesthetic features, new interactions, different users or use cases, etc. In our experience, homing in on one or two viable concepts often causes groups to return to their problem and need statements. As a consequence, the six steps of the *Design Dash*, while linear and bounded, are typically part of an extensive, recursive, and ongoing process of iterative prototyping.

Learning Outcomes
After completing this activity, you should have:

- A clear sense of the problem you are trying to address.
- An idea of who your potential users are, as well as how to avoid making normative assumptions about them.
- A sense of the social context(s) in which you are seeking to deploy your solutions.
- Rough sketches of several possible solutions that address the underlying needs of your potential users.

Learning Resources
- Buxton, W. (2007). *Sketching user experiences: Getting the design right and the right design*. San Francisco: Elsevier/Morgan Kaufmann.
- Greenberg, S., Carpendale, S., Marquardt, N., & Buxton, B. (2011). *Sketching user experiences: The workbook*. San Francisco: Elsevier.
- Ratto, M. (2011). Critical making: Conceptual and material studies in technology and social life. *The Information Society, 27*(4), 252–260.
- Zenios, S. A., Makower, J., & Yock, P. G. (2010). *Biodesign: The process of innovating medical technologies*. Cambridge: Cambridge University Press.

Reference

Greenberg, S., Carpendale, S., Marquardt, N., & Buxton, B. (2011). *Sketching user experiences: The workbook*. Burlington: Morgan Kaufmann.

Chapter 33
Evaluation of Health Technology Solutions

Jay JH Park, Patrick Boutet, Gabrielle Serafini, and Richard T. Lester

The Challenge

Health technology refers to any technologies that can be used to improve the health of an individual, population, and/or efficiencies of health systems. In the digital era with increasing technology accessibility and functionality, the global potential of health technology solutions has grown immensely. Health technology solutions are advertised as having an immense potential in improving the quality of care and boosting efficiency at controlled or even reduced costs. Yet, there is an unmet need by health technology solutions. The current evidence to support widespread implementation of health technology solutions is unclear. This can be attributed to the fact that technological advancement has been made without much consideration of its end users' context of use; diversity (abilities, needs, motivations); understandability; usability; and formal performance testing (reliability, recoverability, privacy, and data security). Evaluation approaches used for health technology solutions also have been largely inadequate.

Evaluation of health technology solutions can be improved by adapting the existing evaluation framework in a *hierarchy of evidence* that is conventionally used for biomedical interventions. To establish a common evaluation framework for health

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technology solutions, it is important to note four general user types of health technology solutions: *clients*, *care providers*, *health systems*, and *data services*. Adapting the evaluation framework to health technology needs to consider specific evaluation metrics and approaches to these users.

In this chapter, we discuss key ideas around an evaluation framework for health technology solutions that include the following concepts:

- Ranking quality of evidence for health technology solutions.
- Classification of health technology solutions based on users.
- Evaluation metrics for health technology solutions.
- Evaluation approaches for health technology solutions.
- Case study: WelTel, a two-way SMS patient case management solution.

Key Ideas

Ranking Quality of Evidence for Health Technology Solutions

Evaluation of healthcare interventions generally follows a framework called "hierarchy of evidence" that was developed for biomedical research in 1995 (Guyatt, Rennie, Meade, & Cook, 2002, pp. 10–12). This framework ranks the evidence by the types of studies that were used to generate the evidence (see Table 33.1). While the hierarchy of evidence framework was not specifically developed for technology research, its core principle can still be generalized to evaluating health technology interventions, since health technology solutions are prone to similar biases as biomedical interventions.

Ranked at the top of the hierarchy pyramid, *randomized clinical trials* (often short for RCTs) are considered by many as the highest valid method when establishing effectiveness and/or safety of a given solution (Friedman, Furberg, DeMets, Reboussin, & Granger, 2015). These studies are experimental in nature and involve comparison(s) of one or more intervention groups to a control group, with the assignment of a group being determined by randomization. In an RCT involving a health technology solution, the participants in the control group will receive

Table 33.1 Hierarchy of evidence

Study type	Quality of evidence
1. Randomized clinical trials	Highest
2. Cohort studies	⇑
3. Case-controlled studies	‖
4. Cross-sectional studies	‖
5. Case reports	⇓
6. Expert opinions and anecdotal experiences	Lowest

standard care, and the participants in the intervention group will receive a health technology solution in addition to standard care. Randomization removes selection bias and tends to produce groups that are comparable in terms of both measurable and unmeasurable factors, so the difference in effects observed at the end of the RCT can be attributed to the received care, as allocation was determined using randomization (Friedman et al., 2015).

Cohort studies refer to observational studies that analyze longitudinal information collected over time (Hulley, Cummings, Browner, Grady, & Newman, 2013). These studies are referred as observational because the researchers do not control what interventions the study group will receive. They can be retrospective (looking back in time) utilizing already collected information from an existing database (e.g., electronic medical records [EMR]) or prospective (forward in time) that collect new information over time, i.e., longitudinal (Hulley et al., 2013). There are risks for possible selection bias, but in instances where running an RCT is not ethical or practical, prospective cohort studies would be the next viable approach to generate quality evidence.

Case-control studies are another type of observational studies where participants are selected based on the outcome. Case-control studies are used to identify factors that may contribute to a health condition by comparing individuals with and without the condition of interest. For example, the *cases* include individuals with the outcome of interest, such as people with mobility challenges, who are then matched with the controls, such as people without mobility issues.

Case-control studies are quick and inexpensive to undertake and therefore are extremely useful for the study of rare diseases. The main challenge with case-control studies is that only probable cause can be established, as the design itself creates difficulties when pinpointing which of the identified factors attributed to the health condition.

Cross-sectional studies are types of studies that involve information collected at a single time-point. These studies are neither experimental nor longitudinal; cross-sectional studies are descriptive as they only describe some feature of the study group at a given time. The difference between case-control studies and cross-sectional studies is temporal; meaning that in case-control studies, the *outcome* of interest is determined and, therefore, is known in advance. Also, the focus is to determine the exposure or factors that may have contributed to the outcome, such as a health condition. In cross-sectional studies, both the outcome of interest and exposure are established at the same time, and, as such, it is difficult to determine whether the exposure predates or comes after the outcome.

Case reports and *expert opinions* and *anecdotal experiences* are ranked at the bottom of the pyramid, as they are most prone to individual biases (Guyatt et al., 2002). Case reports involve narrative summary of very few participants. Usually, they are based on very rare medical cases. Expert opinions and anecdotal experiences are not valid or useful for evaluating health technology solutions because they are unreliable sources of evidence.

It is important to note that *evidence* is understood here as it pertains to evaluation of an intervention for effectiveness. There are many types of knowledge that should

Table 33.2 Classification of health technology based on users

Users		Examples of users
Clients	Any users or recipients of health services	Patients undergoing medical care
Care providers	Any persons who deliver care and services to clients	Doctors and nurses
Health systems	Any systems involved in the oversight of care for clients and care providers	Hospitals and nursing homes
Data services	Data systems responsible for collecting, managing, exchanging, and other data related activities	Electronic medical records

also be constituted as evidence such as one's lived experience, such experiences are important for determining whether the technology is feasible in real-world settings. As such, we would caution against the ascribing our hierarchy of evidence and study design as definitive for all types of research.

Key Idea: Classification of Health Technology Solutions Based on Users

We can classify different health technology solutions based on the user. The World Health Organization (WHO) has proposed a user-based classification for digital health interventions recently: (1) clients, (2) care providers, (3) health systems, and (4) data services (World Health Organization, 2018) (see Table 33.2).

Clients refers to any public members that are users or recipients of health services (e.g., patients), and those who deliver care and services to clients are referred to as *providers* (e.g., doctors and nurses). *Health systems* refer to any systems that are involved in the oversight of the care for the clients and providers, for example, hospitals and nursing homes. The data systems responsible for collecting, managing, exchanging, and other data-related activities that can be used to improve outcome and efficiencies of services are referred as *data services*, for example, electronic medical records (World Health Organization, 2018).

It is important to note that a given health technology solution may typically fall into multiple classifications of users.

Evaluation Metrics for Health Technology Solutions

In general, evaluation can be thought of as an objective assessment of an intervention with the aim of determining its impact and sustainability. In the context of health technology, evaluation can be thought of as an objective assessment of the end user's interactions with the health technology solutions and the changes observed in the users attributed by the health technology solutions. It is, therefore, critical to consider and evaluate the technology based on the following metrics: *usability*, *clinical effectiveness*, *efficiency*, *cost*, *safety*, and *sustainability*.

A health technology solution with high usability will make certain that its end users' needs are met, that the product is understandable and intuitive to use and accomplishes the desired effects, and that the overall user experience is one that is positive. An effective solution will be successful in producing an intended result or outcome. Clinical outcomes refer to the measurable changes in health or quality of life that result from the care that was received. Clinical outcomes are important for determining clinical effectiveness. An efficient solution will achieve a higher degree of outcome without any additional effort. Safety in the context of health technology is not just be limited to health safety (e.g., physical safety), but it should also address concerns of confidentiality, data security, system and/or technology reliability, and system and/or technology recoverability. All of these elements can have an effect on the overall safety of the end user, such as a hospital, EMR system, nurse, patient, etc.

At the outset, it is important for investigators to clearly identify an evaluation plan. This entails identifying specific measures for each set of metrics. Ensuring transparency of the evaluation plan and the assessment approaches across all team members is important.

Consider these questions, posed as illustrative purposes and are not meant to be comprehensive, which may be used:

Usability:

- Is the health technology suitable for use by older patients undergoing medical care?
  - Is it easily understandable? Does it allow them to accomplish the specific task? Is the overall user experience positive?
- Does the health technology fit within the workflow of the care providers?
  - Is the technology solution conducive to the everyday work experiences of health care providers (e.g., nurses, general practitioners)?

Clinical effectiveness:

- Does the health technology lead to improved disease control when compared to existing standard of care?

Efficiency:

- Does the health technology solution make the jobs of care providers easier?
- Does it reduce time to care delivery?

Cost:

- What is the overall cost for implementation?
- What is the cost to maintain and train users?

Safety: User protection:

- Does the health technology meet the ethical and legal requirements for hospital settings?
- What measures are implemented to protect the digital privacy of patients?
- What measures are implemented to protect against system and/or technology intrusion?
- If the technology fails, does it recover elegantly? Does it protect against any data loss?
- How critical is the role of the technology and what are the implications if it fails and is unrecoverable?

Sustainability:

- How is it funded? What are the implications for sustainability if funding is lost?
- Will the health technology continue to operate if the environment it is deployed in changes (e.g., EMR changes; shuffle of employees and/or closing a department; computer operating system is no longer supported; etc.)?

Evaluation Approaches for Health Technology Solutions

Robust evaluation approaches are needed to determine the validity and reliability of health technology solutions. To test the usability of a health technology solution, it is important to seek feedback directly from the users themselves. For instance, if the solution is intended for use by healthcare providers, acquiring their feedback on usability, for example, user interface and other functionalities, is important if the solution is to be integrated as part of their regular workflow.

To evaluate a health technology solution, an RCT design may be the most appropriate. An RCT is the most valid form of evaluation to measure a solution's clinical effectiveness, i.e., the solution's ability to achieve improved clinical outcomes. Also, a cost-benefit analysis component could be incorporated into the RCT, such that efficiency and cost evaluation can be done as well.

However, for biomedical interventions, there are often ethical and/or practical constraints that can limit the possibility for conducting an RCT. Conversely, for health technology solutions, ethical issues around randomization are minimal if the standard care is provided to all participants regardless of their randomized assignment between groups. There are still practical constraints, as there may not be enough people willing to participate in an RCT. In such cases, other evaluation approaches, for example, prospective studies, may be used. However, it is important to recognize the potential bias that may exist with these approaches.

In terms of cost assessment, it is important consider the overall costs incurred including the ensuing costs if the desired outcomes are achieved. For instance, there are many costs associated with implementation, sustainability, and ongoing operation over time. Lessons learned in this chapter are demonstrated by a case example in Box 33.1. Details of the application and the impact of WelTel are further described in the accompanying case study.

Box 33.1 WelTel Case Study

Effectiveness
In November 2010, the WelTel solution was announced as a late-breaker at the mHealth summit as having been tested in an RCT and shown to improve adherence to life-saving antiretroviral therapy (ART) for persons living with HIV in Kenya. This landmark trial showed that a simple patient case management solution could lead to relative risk reduction of almost 20% for nonadherence to ART. Since then, WelTel has undergone several assessments using various high-quality evaluation approaches via prospective longitudinal studies, qualitative studies, and other methods of evaluation. Throughout that process, WelTel's technology solution has remained robust, reliable, and valid at improving outpatient engagement in care and case management.
Efficiencies
The communications are captured via a Web interface that is mobile device friendly and organized for intuitive provider access and clinical workflows (provider case management). The system records all communications and patient-centered care plans can be noted. A video component has been integrated for optional use in settings where smartphone access and sufficient data connections are available. However, the *base of the (economic and digital) pyramid* approach is maintained by ensuring access to the platform through basic cell phones to ensure access for any user. In addition, WelTel can send the patient clinic appointment reminders via SMS. Provider-side alerts tailored to specific patients can be shared between different colleagues who operate in team-based care settings. Overall, the system's ability to triage the urgency of patient-reported issues can help identify which patients require additional support and when they need it.
Cost
Total overall cost to implement, train care providers, and maintain the WelTel solution is minimal. WelTel operates on a subscription-based system that can range from US$5–15 per patient per month in North America, to less than US$10 per patient per year in parts of Africa. Of course, wider, enterprise implementation of WelTel's solution will ensure that economies of scale are achieved making the cost per patient significantly lower.
The economic analysis of WelTel supporting HIV care in Kenya was found to be *extremely cost-effective* by WHO standards at below $15 per patient per year, and for treatment of LTBI in Canada, a simulation study indicated a 10% improvement in adherence would be cost-effective up to $220 per intervention. Despite emerging evidence, transforming *evidence to action* at scale remains challenging as pathways for scaling digital health services remain less well established than for treatments and diagnostics. Clear or coordinated implementation policies will be required at country and regional levels for digital health services to reach their potential.
Safety
WelTel's solution has been tested in real-life situations to protect the safety of patients, and it has never had an accidental disclosure. As human rights violations have unfortunately been common in different regions of the world, WelTel was sure to impose the highest level of security and safety measures in its design architecture to protect patient confidentiality and prevent accidental disclosure of HIV status. In pursuit of maintaining this standard, a high level of training was offered to care providers around language concerning HIV in text communication with the patient.
WelTel complies with all security and privacy standards for Canada, the United States, Kenya, Rwanda, South Africa, and European Union and can meet the requirements of any other geographical settings.

(continued)

Box 33.1 (continued)

Plans for further technological development
WelTel's technological development plans will always incorporate the core principle of inclusion. We will continue assessing opportunities for inclusion with advancing and emerging technologies while ensuring that the most vulnerable people and populations always have access to care. In doing so, WelTel will seek to fill evidence gaps to identify best practices for patients and providers and to assist with the enterprise implementation process to have maximum positive impact on population health.
The immediate specific plans for technological development include incorporation of natural language processing (NLP) capacity for WelTel. By looking at patient-care provider SMS communications and utilizing such methods as topic modeling or sentiment analysis, WelTel solution will have the potential to identify patient reported priorities or health-seeking behaviors over time, across populations, or right down to a single patient.

Product Innovation Pathway (PIP) Model

As already noted, evaluating the validity and reliability of health technology solutions is important. Many of the ideas presented in this chapter fit into different steps of the PIP model. It is possible to identify some key activities of evaluation that are linked to the model, as seen in Table 33.3.

Learning More
The book is an introduction to the complex world of evaluation research. It is important for readers to stay informed with ideas for their next steps and sources of additional information. These two sources provide a good foundation of information:

- Guyatt, G., Rennie, D., Meade, M., & Cook, D. (2002). *Users' guides to the medical literature: a manual for evidence-based clinical practice* (Vol. 706). Chicago: AMA Press.
- Hulley, S. B., Cummings, S. R., Browner, W. S., Grady, D. G., & Newman, T. B. (2013). *Designing clinical research* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.

Key Messages
The pace of technological advancement will remain rapid. However, without considering how future health technology solutions affect different users, the potential of health technology will continue to have an unmet potential. We have introduced an existing evaluation framework and illustrated how it can be specifically adapted to health technology. As a case study, we introduced a Canadian company with a health technology solution. WelTel has undergone several iterations and extensive

Table 33.3 Product Innovation Pathway (PIP) model: evaluation plans for health technology solutions

PIP level	PIP description	Key activities
1	Innovative ideas (conceptualization)	When initially thinking about a health technology to evaluate, at a high level, keep in mind *usability*, *clinical effectiveness*, *efficiency*, *cost*, *safety*, and *sustainability*, and review different sources when looking for evidence regarding the health technology under consideration
2	Planning	Attempt to promote transparency in each activity that comprises the overall evaluation process; use hierarchy of evidence to assess quality of evidence; identify who will be the user classes of the health technology Consider different evaluation approaches feasible for a given solution based on its user classification; explore existing contacts and identify user representatives; consult user representatives for key considerations for evaluation as well as researchers with experience and with expertise in evaluation
3	Development	When choosing the deployment environment, it is important to consider this as the overall environment where the evaluation will be executed and should be representative of its use in practice; select key metrics to observe during the evaluation; specify an evaluation approach that includes pre-specified evaluation metrics ahead of time; evaluation protocols may be registered ahead of time for planning and transparency purposes
4	Testing in real-world environment	Carry out the evaluation using the protocol developed ahead of time; testing should assess for user feedback during the evaluation
5	Outcomes and impact	Reporting negative or positive findings on evaluation; if negative findings are observed, then consult the users for feedback, and make iterations to health technology solution; findings should be clearly linked to evaluation metrics

development after being evaluated for its usability, effectiveness, efficiency, cost, and safety. Lessons that can be drawn from our discussion include the following:

- It is important for technology developers to consider and develop evaluation plans for their health technology solutions.
- The quality of evidence (or strength of your evidence) may be ranked using the hierarchy of evidence framework provided.
- For evaluation plans, it is important to identify the intended users and engage them early, during, and after your evaluation.
- It is important think about a health technology solution in terms of its usability, clinical effectiveness, efficiency, cost, safety, and sustainability.
- To achieve empirically relevant evaluation outcomes, the sampled users should represent and match the end users, and the number of those sampled should be adequate and nontrivial (e.g., two people are not enough for adequate evaluation).

References

Friedman, L. M., Furberg, C., DeMets, D. L., Reboussin, D., & Granger, C. B. (2015). *Fundamentals of clinical trials* (5th ed.). Cham: Springer International Publishing.

Guyatt, G., Rennie, D., Meade, M., & Cook, D. (2002). *Users' guides to the medical literature: A manual for evidence-based clinical practice* (Vol. 706). Chicago: AMA Press.

Hulley, S. B., Cummings, S. R., Browner, W. S., Grady, D. G., & Newman, T. B. (2013). *Designing clinical research* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.

World Health Organization. (2018). *Classification of digital health interventions v1.0: A shared language to describe the uses of digital technology for health*. Geneva: World Health Organization.

Chapter 34
Case Study: WelTel Solution—An Interactive SMS-Based Mobile Phone Support for Patient-Centered Care

Jay JH Park, Gabrielle Serafini, and Richard T. Lester

Almost all healthcare is voluntary. Patients choose when to engage in care, when to take medicine (if they choose to), and whether to return for follow-up visits. Without adequate patient engagement and care that centers on patients, their management can be challenging, especially for chronic diseases. Mobile health (mHealth), the application of mobile technology for the provision of healthcare support to patients and care providers, has shown great promise. mHealth is increasingly being integrated into existing healthcare systems to improve access, engagement, and delivery of health services. However, the vast majority of proposed mHealth solutions have not been tested. Nor have they adopted the core value of patient-centered care that is critical in improving quality of services and long-term patient health outcomes. Instead, mHealth is commonly used as a reminder.

WelTel Inc. (www.weltel.org) is a Canadian-led patient communication and outpatient case management tool that is recognized as a world leader in the field of mHealth. This health technology solution was initially designed to address the problem of adherence for patients initiating antiretroviral therapy (ART) in Africa (Lester et al., 2010). WelTel has since expanded its application to include a wide

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range of other conditions and settings including primary care; tuberculosis; asthma; maternal, newborn, and child health; as well as preventative health in different regions across North American, African, and European countries. WelTel uses mobile phones and SMS at the base of its pyramid through an interactive tool for care providers to communicate and engage directly with their patients.

In the last two decades, WelTel has led the global medical field in evidence for outpatient digital clinical support by focusing on patient communication as the first priority followed by monitoring and reporting. With over $4 million dollars in research and development, WelTel's rapidly growing service platform is currently in its fifth iteration that has been created based on patient and provider preferences. WelTel has undergone several iterations after using the *hierarchy of evidence* evaluation framework adopted for digital health solutions. The evidence suggested that empowering patients through self-efficacy is more effective at improving health outcomes than monitoring alone. WelTel offers a patient-centered care solution because it was specifically and purposefully designed for patient engagement from its inception. The WelTel solution works by encouraging the patient to self-manage and gives them critical access to care when needed. This enforces and reinforces long term provider–patient relationships for engagement and patient-driven self-management.

Based on field research with patients and frontline providers to inform preferred messaging content, frequency, and process, the system sends automated text message check-ins to registered patients asking them: "How are you?" (in any preferred language) on a weekly basis (or at any other frequency). The patient can respond by text with "OK" or "Not OK" to indicate a need for communication with the healthcare provider who can respond using text, voice, or video outreach when appropriate.

The communications are captured via a Web interface that is mobile device friendly and organized for intuitive provider access and clinical workflows (provider case management). The system records all communications and patient-centered care plans can be noted. A video component has been integrated for optional use in settings where smartphone access and sufficient data connections are available. However, the *base of the pyramid* approach, both economic and digital, is maintained by ensuring access to the platform through basic cell phones to ensure access for any user. In addition, WelTel can send the patient clinic appointment reminders via SMS. Provider-side alerts tailored to specific patients can be shared between different colleagues who operate in team-based care settings. Overall, the system's ability to triage urgency of patient-reported issues can help identify which patients require additional support and when.

WelTel is a globally adopted patient-centered solution being used in countries such as Canada, the United States, Kenya, and Rwanda. WelTel has demonstrated improvements in patient care and outcomes for a range of chronic conditions such as human immunodeficiency virus, tuberculosis, and asthma. WelTel is being used to support Vancouver's downtown eastside homeless and injection drug user population and pregnant women living in rural regions of Kenya at risk for preeclampsia and other adverse pregnancy and birth outcomes. From our experience of delivering the WelTel solution over the last 15 years, we know that the frontline users (e.g., community health workers, nurses, physicians) appreciate a tool that is intuitive, user-friendly, and straightforward. This was the drive to keep the WelTel platform's design purposefully simple. WelTel uses a color-coded, graphical user interface that any care provider can use. WelTel designed its operational features to blend into the daily practice of patient-centered care and management.

Key Messages

- Patient-centered care is critical for patient management and support, especially for chronic diseases that require lifelong voluntary engagement from the patients.
- For digital health solutions to be integrated into and be used within the existing healthcare systems, simplicity is key.
- The design and subsequent iterations of digital health solutions can be made after undergoing evaluation using the adapted *hierarchy of evidence* framework.

Project Details and Team Current team members of WelTel include project leads, Drs. Richard Lester and Gabrielle Serafini, alongside a transdisciplinary team of several healthcare providers, software engineers, contractors, and customer development partners who live and work across North America, Europe, and Africa to provide WelTel solutions to various global regions.

Reference

Lester, R. T., Ritvo, P., Mills, E. J., Kariri, A., Karanja, S., Chung, M. H., … Plummer, F. A. (2010). Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya1): A randomised trial. *Lancet, 376*(9755), 1838–1845. https://doi.org/10.1016/S0140-6736(10)61997-6

Part IV
Creating Research Products

Alex Mihailidis and Andrew Sixsmith

The final part of this book is concerned with getting the outcomes of research into the hands of the people and organizations that will benefit from them. These outreach activities are typically seen as "end of project" activities, or the final knowledge translation that comes after the research has been completed. The product innovation pathway (PIP) model presents "implementation" as the final level of action, and there is certainly a major shift in emphasis for knowledge production to knowledge action. However, as discussed in the initial chapters, a key idea is that there are many of these outreach actions needed to be brought forward, or at least considered, throughout the project life cycle. For example, doing some early work on commercialization (e.g., developing early business plans or canvases), or ensuring that there is appropriate management of intellectual property (IP) in place (e.g., filing IP disclosures or filing for provisional patents), is crucial for avoiding problems later on. This book also argues that effective research based on integrated knowledge mobilization implicitly involves an iterative approach that closely connects the research and outreach activities. This part looks at different types of outreach activities:

- Policy and practice—developing and implementing action plans and new service models that will enhance health outcomes or improve the efficiency and effectiveness of services.
- Commercialization—exploiting the business opportunities afforded by technologies or new consumer services that people will buy and use.

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- Knowledge—communicating knowledge to different audiences with the aim of having some kind of behavior change that will have health, social, or economic impact.

It is not feasible to cover all these in any kind of depth in this book, and our aim is to raise awareness and provide the reader with some of the key ideas and practical resources that will help them accelerate the implementation and adoption of their solutions.

In Chap. 35, Polanyi et al. focus on how to communicate effectively with different audiences, including the public, policy makers, industry, and the media. Researchers are expected to publish their work in academic journals, but relatively little effort (or credit) is given to communication to other audiences. This has changed to some extent, for example, with scientists and researchers gaining a wider audience through social media and video platforms. However, real-world impact requires a greater emphasis on communication to the public and particularly to decision-makers and influencers. The chapter emphasizes a proactive approach to communications, and researchers should be actively looking for opportunities to reach their audiences. This is not always easy, and working with communications specialists may be an effective solution. A key aspect of outreach in the modern era is the effective use of project websites and social media, and the chapter provides some practical advice on these. The two case studies that go with Chap. 35 provide some practical insights and advice. The case study on “Reaching a wide audience” highlights the media impact of the “Rate My Treads” project that evaluated the effectiveness of winter footwear in slippery conditions. It shows how researchers can work closely with communications professionals to have an impact on the media and the public. The case study “Writing Stuff for the Real World” provides some simple guidelines for accessible communication and how researchers should be communicating at all stages of their project.

Chapters 39 and 41 focus on how researchers can interact and influence the world of policy and practice. In Chap. 39 Simeonov et al. look at how researchers can accelerate the uptake of new policy-related ideas and information through partnerships with decision-makers. The chapter provides ideas on how to build collaborative partnerships with policy and decision-makers. As well it discusses some of the tools that can be used to get the results of research into the public policy development process. The case study “From stakeholder engagement to policy change” highlights the Silver Alert initiative in Alberta, Canada, where the project team worked with legislators to implement missing persons legislation in relation to people with cognitive challenges. In Chap. 41, MacNeil et al. look at how researchers can navigate the complex worlds of policy, regulation, and health systems. This is a major challenge for researchers as these can vary in different countries and provinces. It is important to understand these jurisdictional and regulatory landscapes. Understanding and shaping the solution to the target market or the health-care system are also important to eventual success. A key challenge is to provide the right kind of evaluation and evidence that will present a compelling value proposition to potential funders and providers or fulfill regulatory requirements.

Chapters 42 and 45 deal with the commercialization of products and services. This is particularly important in the fields of medical devices, assistive devices, health-care technologies, and eHealth. If new technologies are to get into the hands of the people who are going to benefit from them, then they need to be turned into commercial products that can be manufactured and marketed. Commercialization is becoming less of a dirty word within academic circles and, indeed, in recent years has seen a huge growth in markets for health technologies. Even if researchers are not going to get involved directly in the commercial ventures (e.g., through a start-up), they need to be aware of the route to market and plan accordingly. In Chap. 42, Battersby and Viswanathan provide a beginner's guide to commercialization. The researcher will need to determine the right route to market, e.g., start-up or licensing, as well as the product having a clear value proposition. The chapter also provides some practical advice on fundraising and building a business model. The two case studies provide examples of how the outcomes of research projects were successfully commercialized. In Chap. 45, McAloney et al. deal with the challenge of dealing with IP. The term IP refers to the commercially valuable assets that may be created by a project, and managing, protecting, and exploiting this IP is a major task in itself, over and beyond the core research and development activities in a project. The chapter focuses on actions that researcher should be taking early on in their projects.

Finally, in Chap. 47, Simeonov et al. look at the idea of integrated knowledge mobilization (KM) and provide some straightforward guidelines for how this approach can be applied within a research project. KM is about the dynamic connection between the research activities and the real-world strategies required to develop appropriate solutions and working toward getting these adopted and used by the people who will benefit from them. The key aim of KM is to establish meaningful engagement with relevant stakeholders and work with them to refine the research, define KM goals, as well as carrying out and evaluate outcomes. The learning activity linked to this chapter focuses on a practical approach to integrated KM in the field of assistive technologies. The activity involves setting up a small-group session to explore and evaluate the value proposition and likely adoption and use of a new assistive technology.

Chapter 35
Effective Communications

Margaret Polanyi, Dorina Simeonov, and Elise Johnson

The Challenge

Today's researchers are expected to communicate widely about their research. The engaged researcher embraces opportunities to connect with a broad range of audiences that includes government, industry, community organizations, and the general public. Effective communications can help researchers to share expertise, build awareness of their work, and achieve greater impact. Communicating about your research is a way to inform public discussion, influence decision-makers, and become a thought leader. Moreover, you can directly reach people who will benefit from your work. Strong research communications can make you a *go-to* authority for media and lead to new collaborators, students, funders, and study participants. The challenge is for you to know how and when to reach out. Some researchers may be reluctant to engage in communications when their research is in its early stages or if their research is highly complex. The truth is that there is always some element of your research that you can communicate. It's not enough to wait for a call from a journalist or from the communications specialist at your institution. In this fast-moving digital age, it's particularly important to be proactive; otherwise opportunities will be lost to you. This chapter contains some key ideas that will help you to communicate effectively about your work:

- Developing an elevator speech.
- Milestone moments.
- Involving a communications specialist in all stages of your research.

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- The value of a website.
- Leveraging social media.

Key Ideas

Developing an Elevator Speech

The question can come at any time, from anyone: What kind of research are you doing and why is it important? The answer may need to be delivered in the time it takes to ride an elevator to a meeting. It's important to be ready with an explanation that can be delivered in succinct and compelling lay language. This doesn't mean oversimplifying—just simplifying for the benefit of those outside your academic circle. Your elevator speech may be for a government representative, industry member, journalist, member of the public, or a researcher in another field. Your explanation should touch very briefly on the problem you are addressing, your goal, what you have learned so far, and why it is important. Show your passion for your work when you deliver your elevator speech. If the research is complicated to explain, use an analogy. Make your explanation conversational—this is not actually a speech. Some researchers think of it as a *headline*. Aim for a minute in length, but be prepared to make it less. It depends on the circumstances. Be ready to add a few words as a closer that are tailored to your listener. People can always follow up with questions—but only if you capture their interest in the first place. The elevator speech will need practice. Try it on acquaintances and adjust it, depending on their reaction.

Milestone Moments

New outputs and outcomes, such as the publication of important findings or a product launch, are key times to engage in communications. However, there are many other milestones and moments that can be shared along the way. They may not always seem like front-page news to you, but developments of all kinds can generate content for your social media channels, your institution's website, or perhaps a news report (see section "Involving a Communications Specialist in All Stages of Your Research"). If you think of yourself as a content provider, the possibilities for communicating about your research are abundant. Reach out, for example, about a new research grant, the start of a clinical trial, or an interesting collaboration. Awards, honors, and conference presentations are great reportables. So are moments like the 100th participant recruited to a study or an intriguing new feature for the technology you are developing. The arrival of an unusual piece of research equipment can be fascinating—for example, the story of a team that used a crane to lower an apparatus into their lab. Researchers commercializing products will find plenty to share, whether it's a new design for a health app or the start of Beta testing. On a cautionary note, many academic journals will not publish results that have already been reported. If in doubt, check with the journal that has accepted your paper. That said, there are a myriad of opportunities to get the word out about your research without imperiling publication.

Involving a Communications Specialist in All Stages of Your Research

Think of the communications specialist at your institution as a gateway to numerous opportunities to raise awareness of your research and help you achieve an impact with it. Make sure the individual responsible for communications is aware of key developments with your research (see section "Milestone Moments"). Reaching out can be as simple as sending a brief email about a new grant or about a paper of potentially broad interest that has been accepted for publication. (Any form of publicity can be timed to coincide with publication by a journal.) At any given time, communications specialists are working on an array of initiatives including annual reports, newsletters, website content, webinars, media pitches, news releases, videos, and social media campaigns. There are also special events showcasing research to audiences such as government officials, donors, and the public.

Your communications specialist is always looking for stories about exciting research, outcomes, and impact. These specialists have the skills and training to communicate with diverse audiences, and they are your best conduit to the media. In fact, most institutions ask that, if you are contacted by a journalist, you refer the caller to their communications specialist. Do this promptly as journalists typically have tight deadlines. The communications specialist can get details about the interview request, including topics to be discussed, format, and whether there are other interviewees, before a decision is made whether to do the interview.

Box 35.1 Getting the Call: Media Interviews

It's natural to be anxious about doing a media interview. There is every reason for it to go well—if you are prepared. Before the interview, think of a couple of key messages you want to get across. Ensure you have the essential facts at your fingertips. Some researchers like to do a practice run with a colleague. During the actual interview, use plain and jargon-free language (see section "Developing an Elevator Speech"). Keep your answers short and conversational. Reinforce a point with a brief anecdote or a personal experience. Assume that everything you say is on the record. If you don't know an answer, it's best to simply say so. You can refer the journalist to another source or, if the interview is not live, follow up afterward with the information. Avoid confidential matters, including patient names (unless the individual has signed a consent form). Segue to your key messages, and remember to convey why your work is important. Exude enthusiasm—it can be infectious.

The Value of a Website

Your own website is an important communication vehicle for sharing your research. Having a website will increase the number of people who view your publications, recognize your name, and cite your research (Biggerbrains, 2012). Below are practical steps to creating a research website.

Determining the Purpose

There are many reasons to create a research website. Depending on your goals, you can aim toward one of the websites below and include the following content:

- Individual researcher website: research interests, publications, and your CV.
- Research program or lab website: research projects, progress, findings, profiles of team members, and career opportunities.
- Individual project website: findings and recommendations for diverse audiences.

Your website can include other elements such as links to media stories about your research or videos explaining key concepts. If your website is going to be publicly available online, you need to take this into consideration and ensure you are writing in plain language. This is a good time to reach out to a communications specialist at your institution to find out if there are any policies in place for creating a new website. There are guidelines you may need to follow and you will want to verify if approval is needed.

Planning Your Website

Once you have determined what you want to create, you can start planning. Here are a few questions to ask yourself:

1. What is my budget? Outsourcing the creation of your website can cost anywhere from $500 to thousands of dollars. If your budget is limited, consider connecting with other departments in your organization that may have the skill set, or have students looking for opportunities. There are also online tools that allow people to build a website for free. For more information, read the *Definitive Guide—How Much Should a Website Cost You?* (https://www.websitebuilderexpert.com/building-websites/how-much-should-a-website-cost/).
2. What domain name should I use? If you are creating a standalone website, consider using a combination of your name and initials e.g., wturner.com. Avoid hyphens or numbers (Biggerbrains, 2012). You can register your domain online.

3. Who will host my website? Domain names and hosts can go hand-in-hand. The hosting provider gives the virtual location and server where your website will be stored and managed (Biggerbrains, 2012). Domain companies also offer this service. Check if your institution is able to host your website on their server.

Creating Your Website

Here are four tips to ensure that your website is an effective tool to share your research:

1. Choose a content management system that is right for you. Some examples include Squarespace, Wix, and the best known, WordPress. If you have no previous experience in creating websites, Squarespace has excellent templates and Wix provides an easy drag-and-drop interface. WordPress is good for blogs and more advanced users, if you want to take advantage of the plug-ins (i.e., add-ons to your website that provide additional functions).
2. Build a website that is accessible and appropriate for any device (University of Oxford, 2018). Many organizations are abiding by the international *Web content accessibility guidelines* (WCAG) 2.1 when creating websites (Cooper, Kirkpatrick, & O'Connor, 2018). Ask your communications specialist what level of this guideline your organization is using.
3. Write for the Web. Online, readers tend to scan pages and look for headings and summaries near the top of the page. Put the most important information at the top and include many images to keep the reader engaged (University of Oxford, 2018).
4. Maintain your website. Keep your content up-to-date. Having a static website makes it look less credible and people are less likely to come back.

Box 35.2 Using Visuals to Attract Interest

Powerful visuals will greatly enhance the appeal of your communications outreach. Images that show people doing things and research in action are more interesting than posed or stock shots. Build an image library that you can draw on for your website, social media, posters, and presentations. Make an infographic, which is a visual image used to represent data or information. Consider creating or commissioning a video about your research and its outcomes. Videos can have tremendous reach and impact. If you have funds to hire a professional videographer, your video will have higher production values, such as proper lighting, clear audio, and strong storytelling. You can also tap a team member who has the right skills and equipment. Your video should be less than 5 min long. Posting to YouTube will give it wide exposure. If you are sharing your video on social media, aim for a minute or less in length. Before releasing any video or image publicly, you will need to get written consent from anyone shown. Ask your communications specialist for a consent form.

Leveraging Social Media

Social media is a way to connect with diverse audiences including fellow researchers, funders, journalists, and the general public. Researchers increasingly use social media to learn and share findings, collaborate, advocate, and promote thought leadership in their fields.

Start by Picking a Platform

Mainstays of social media include Twitter, Facebook, LinkedIn, and Instagram. Their prominence and functionality continue to evolve.

Twitter is a favored platform among scientists (Collins, Shiffman, & Rock, 2016), offering access to a "virtual department" far larger than academic departments (Darling, Shiffman, Côté, & Drew, 2013). The distinguishing feature is the fast-paced news stream, which makes it an ideal tool for researchers to share findings and publications, connect with other academics, engage with specific interest groups, and offer commentary on larger social issues.

Facebook has a number of advantages for researchers. Those looking to grow start-ups can build company pages to share information. Facebook Live, the platform's built-in live streaming service, is an easy way to showcase events such as presentations, lab tours, or informal interviews. Some researchers are using Instagram to promote their work and give followers a glimpse into their daily lives through photos and short videos. LinkedIn lets researchers enhance their visibility by networking with other professionals and authoring articles and commentaries. You can also create and join special interest groups.

Box 35.3 Why Researchers Must Tweet

When Dr. David Juurlink, a researcher at Sunnybrook Health Sciences Centre in Toronto, Canada, asked followers to retweet his post to demonstrate reach and value of social media for scientists, he received more than 12,600 retweets.

"Twitter affords an element of visibility that brings a variety of opportunities, from media to networking to expanding the horizons of your research area," says Dr. Juurlink, who has over 22,000 followers on Twitter (D. Juurlink, personal communication, 13 February 2018). His research is focused on toxicology, and much of his Twitter activity is related to drug and opioid issues. In Canada, and increasingly internationally, Dr. Juurlink has become a go-to drug safety expert for journalists. Dr. Juurlink says much of his media exposure is due to his activity on Twitter: "Journalists won't invite you to comment on a story if they don't know you exist." His Twitter activity has also opened doors to speaking engagements and increased his networking worldwide with scientists in his field and related fields.

What to Share

The most popular posts on social media engage and offer something specific to users. It's all about *shareability*—whether that's publications, media articles, or a commentary on research, social issues, or policy matters. It is important to remember to use visuals. A marketing study showed that, on average, visual content performs 4.4 times better than text-based content alone (Chute and Digiday, 2015). Ensure that you adhere to copyright rules when using images or visuals that you did not create.

Ways to Participate

How you leverage social media depends on the amount of time you want to invest and what you hope to get out of it. Below are some ways to experience social media.

Consuming

A social media consumer views content without contributing their own. You might read journal articles, follow leaders in your field, or keep abreast of policy decisions.

Information Sharing

Share some of your work in progress while being mindful of the ability to publish at a later date. Consider posting your team's research findings (statistics, infographics, links to your website), photos of life in your lab, and journal or news articles.

Social media platforms are inherently social. Try engaging with new audiences by live tweeting about an event you are attending. Another option: Tweetchats. Use a hashtag to create a community Q&A session on a specific topic.

Thought Leadership

Become known on social media for your expertise and your commentary by curating what you share. For example, if you are a cardiac researcher, share publications, articles, and insights on cardiac research and patient care.

Table 35.1 Social media etiquette

Do's	Don'ts
Add a personal photo, brief bio, and research website link to your profile. People are more likely to interact with you if they know who you are	Don't post unprofessional or disrespectful content. Always remember that nothing is truly private or temporary on social media
Make your content engaging by including images, videos, statistics, or lists. People like content that teaches something quickly	Don't breach privacy or publish patient information. Posting photos and videos of patients, guests, staff, and volunteers is typically prohibited without obtaining consent. Always check with a communications specialist
Be social. Commenting and replying to posts helps you connect with audiences outside of your usual circles	Don't offer medical advice or argue with patients. If you are using social media as it relates to your work, get approval, and read the corporate and social media policies
Use hashtags—words or phrases preceded by a hash sign (#) identify specific topics and connect like-minded users. Try disease-specific hashtags (e.g., #osteoporosis)	Don't overuse hashtags. While you may be tempted, remember that too many hashtags can clutter your content. Stick to one or two

Partner with Professionals

Ask the communications specialist at your institution for help in creating engaging social media content and setting up initiatives like Tweetchats or Facebook Live events.

Effective Communications and the Product Innovation Pathway Model

Key communications activities that tie into the Product Innovation Pathway (PIP) model can be found in Table 35.2.

Finding Support
Some institutions and funding agencies offer media training workshops to help researchers hone their elevator speeches and interview skills. Your institution's communications expert can share tips on communicating about research, as well as advice and rules for using social media in relation to your work.

Additional sources include:

- Ideas for honing your elevator speech at https://www.nature.com/naturejobs/science/articles/10.1038/nj7435-137a.
- Elsevier's interview tips at: https://www.elsevier.com/connect/11-tips-for-giving-a-great-interview.

Table 35.2 Product Innovation Pathway (PIP) model—effective communications

PIP level	PIP description	Key activities[a]
1	Innovative ideas	Discuss the different audiences you will want to reach. Develop an elevator speech
2	Planning	Contact the communications specialist at your institution and share details about your project. If you are creating a website or using social media in relation to your work, obtain necessary guidelines and approvals. Start work on website design and content. Decide which social media channels you will use
3	Development	Capture images and video of your research in action (ensure you have consent). Alert your communications specialist to significant developments, such as a new prototype or product feature, and explore the possibility of an institutional announcement (once your product is ready). Create a short product summary or brochure. This is also a natural time to launch your website and social media platforms and perhaps blog about your research. Report milestones, without compromising publication
4	Testing in real-world environment	The testing stage is rich with communications possibilities. On your website and social media channels, mention achievements like patents or the start of pilot testing. Keep your communications specialist apprised of key developments, including major papers accepted for publication (publicity can be timed to coincide with publication). You may want to weigh-in on an issue in the public spotlight by writing an op-ed piece that draws on your expertise and research
5	Outcomes and impact	Your communications specialist needs to know about outcomes. If an institutional announcement is planned, make yourself available. Use your website and social media to share outcomes with people who can use them. Consider a video to showcase your work and its impact. Talk with the communications specialist about other ways to highlight impact. Keep track of metrics such as website hits, social media impressions, and media coverage

Note: [a]Some of these activities may need to take place across several stages of the PIP, and this list is by no means exhaustive

- The United Kingdom-based Science Media Centre, which offers free pocket-sized interview tip guides that can be obtained by emailing smc@sciencemediacentre.org.
- Mark Carrigan's *Social media for academics* (2016).
- The University of Oxford's guide for writing for the Web: *Making effective websites* (2018) found at https://www.ox.ac.uk/public-affairs/making-effective-websites?wssl=1.

Key Messages

Communications should be an integral part of the research process—not an afterthought. Keep the following in mind:

- Identify opportunities to communicate about your research at every stage of the Product Innovation Pathway.

- Think of your audience. Use succinct and compelling lay language to convey to non-experts why your research matters.
- Engage with the communications specialist at your institution, right from the early stages of your project.

References

Biggerbrains, E. (2012). Creating a simple and effective academic personal website. https://www.elsevier.com/connect/creating-a-simple-and-effective-academic-personal-website.

Chute & Digiday. (2015). Digiday state of the industry visual marketing: scale to win. https://digiday.com/wp-content/uploads/2015/04/Chute_Digiday_SOTI.pdf.

Collins, K., Shiffman, D., & Rock, J. (2016). How are scientists using social media in the workplace? *PLoS One, 11*(10), e0162680. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0162680.

Cooper, M., Kirkpatrick, A., & O'Connor, J. (2018). Requirements for web content accessibility guidelines 2.1. https://w3c.github.io/wcag21/requirements/.

Darling, E. S., Shiffman, D., Côté, I. M., & Drew, J. A. (2013). The role of Twitter in the life cycle of a scientific publication. *PeerJ PrePrints, 1*, e16v1. https://doi.org/10.7287/peerj.preprints.16v1

University of Oxford. (2018). Making effective websites. https://www.ox.ac.uk/public-affairs/making-effective-websites?wssl=1.

Chapter 36
Case Study 1: Reaching a Wide Audience—Rate My Treads

Erica Di Maio

The Challenge

Walking in the winter can be dangerous. It's estimated that more than 20,000 Ontarians visit the emergency room every year due to falls on ice or snow. That's why researchers at Toronto Rehabilitation Institute-University Health Network (TRI-UHN) developed the Maximum Achievable Angle (MAA) Testing Method—to validate slip-resistant footwear on icy surfaces. With the help of WinterLab, a state-of-the-art research facility that can recreate typical Canadian winter conditions, researchers created the snowflake scale to rate the slip resistance of winter boots. The results were published on www.ratemytreads.com to provide consumers with evidence-based ratings on winter footwear and encourage manufacturers to develop safer products. This case study demonstrates how a communications-savvy team of researchers worked closely with their hospital's communications team to amplify research findings, engage industry leaders, and influence consumers around the world.

Concept and Planning: Setting the Stage for Real-World Impact

In 2010, Toronto Rehab's emerging WinterLab facility enabled a team of researchers to study the impact of winter footwear on icy surfaces using real people in a real-world environment. Results would not be ready to share for a while, but the team identified other milestone moments to create awareness of its important work.

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In early 2011, an article in Toronto Rehab's magazine-style research publication described WinterLab—complete with a captivating 3D lab image—and hinted at the footwear testing underway.

Later in 2011, researchers partnered with UHN's communications team to host a media event marking the official opening of Toronto Rehab's Challenging Environment Assessment Labs (CEAL), including WinterLab. Journalists stepped into sub-zero temperatures to experience the challenges of walking along an elevated icy floor while safely fastened to a body harness. A massive media splash followed, with stunning visuals of journalists dynamically reporting on the future of rehabilitation research at Toronto Rehab.

These visually compelling lab demonstrations helped the public understand how WinterLab could provide a tangible solution to a real-world problem: make Canadians safer in the winter by preventing slips and falls. This clear, concise objective laid the groundwork for all future WinterLab communications: keep it simple and visual.

With a cohesive project vision and clear audience in mind, specifically older adults who are more susceptible to slips and falls in the winter, the team created a simple set of key messages used consistently to help people understand *why* they should care about WinterLab's research. These reasons included, for example, statistics on slips and falls, the cost to the Canadian healthcare system, and the value of validating slip-resistant footwear. These messages, paired with striking photos and visuals, helped researchers reinforce their vision throughout the project.

Development and Testing: Staying in the Spotlight, Engaging Stakeholders

Building off media momentum in 2011, and while the research was steadily advancing, researchers engaged the hospital's communications team early and often to proactively pursue opportunities to communicate project milestones.

In 2012, the team's work in progress on footwear testing was mentioned in a multimedia report in *Canadian Geographic* magazine. Additionally, a story in Toronto Rehab's research publication zeroed in on some footwear testing for postal workers at Canada Post.

In 2013, Canadian TV personality Rick Mercer was invited to test footwear in WinterLab to help build awareness and foster credibility with the general public. Today, the broadcast has more than 70,000 views on YouTube. Global News was among other media outlets that covered WinterLab and the footwear research underway.

Researchers also identified an important need to engage meaningfully with industry leaders on how winter boots are manufactured. The team built strong partnerships with Mark's (formally Mark's Work Warehouse) and Vibram, a footwear manufacturer, to test their boots and prototypes in WinterLab. Researchers also connected regularly with the American Society for Testing and Materials International and the Canadian Standards Association (CSA) Group that are responsible for creating safety standards to receive valuable feedback on their WinterLab testing protocol. These relationships enriched communications efforts and drove an important industry dialogue on using people in a real-world environment to set and validate safety standards.

Implementation: Building an Online Presence, Creating a Campaign

By 2015, the team was frequently getting requests for updates on the project's progress. Rather than publishing one-time results, the team opted for a user-friendly website. The site would enable real-time ratings that appealed to consumers. Search engine optimization best practices were used to help the site rank higher in search results.

In November 2016, a coordinated public relations strategy garnered international publicity for the website, including a press release, photos, 30-s video of testing, and an extensive social media strategy targeting relevant stakeholders. Each media pitch included an invitation to journalists to put their own boots to the test. The campaign was strategically timed for consumers to use the snowflake scale to purchase winter boots ahead of the first forecasted snowfall.

Outcomes and Impact

Following the launch of Rate My Treads, there was an outpouring of support from the public. In 3 months, website traffic soared with more than 2,000,000 visits and hundreds of consumer testimonials. There was a flurry of media activity, with requests from reporters to visit the WinterLab; this resulted in more than 200 national and international media hits on the project. The social media outreach strategy saw tremendous engagement, with more than 32,000 views globally for the 30-s video created by UHN's communications team.

Stores ran out of stock for the top boots listed on Rate My Treads. Researchers received between 20 and 30 inquiries from footwear companies about testing their boots in the WinterLab. Both Mark's and Vibram published their own press releases, proudly acknowledging their boots received Toronto Rehab's seal of approval. Rate My Treads' shoe tags were created for Mark's boots to engage consumers in-store at the point-of-sale.

Key Messages

- Create your headline: Keep it simple. Summarize what you hope to achieve in one sentence and repeat this in every interaction you have. Consistency helps reinforce long-term vision. Researchers used this *headline approach* throughout the process, and the public relations strategy followed suit to communicate research results to the public in a simple, powerful way.

- Think visually: Researchers were able to demonstrate impact through compelling photos and visuals. Rigorous documentation is an important part of a project's life cycle, to help key audiences understand how a solution moves from idea to inception. Simple photos and video can be produced through mobile devices and cost-effective technology.
- It takes a village: Get the right knowledge and expertise at the table from the beginning; engage your organization's communications team and relevant stakeholders early and often. It takes a collaborative team to translate an idea into meaningful change and action.

Project Details and Team Rate My Treads Research and Web Team: Dr. Geoff Fernie, Dr. Yue Li, Amy Liu, Barry Westhead, Wayne Cheng, Benjamin Leaker, and Janakan Srimurugan. Hospital Communications Team: Erica Di Maio, Ana Gajic, and support from UHN's Public Affairs team. Special thanks to partners: Mark's, Vibram, ASTM International, CSA Group, Canada Post, Ontario Ministry of Labour, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

Note. Toronto Rehab's research arm was subsequently renamed The Kite Research Institute at UHN.

Chapter 37
Case Study 2: Writing Stuff for the Real World

Andrew Sixsmith

The Challenge

Academic writing is highly specialized and requires the writer to communicate to a (relatively small) group of his or her scientific peers at a conference or in a scientific journal. While the research results may have important messages for the public, for businesses, policy makers, and practitioners, these journal articles are often not accessible nor understandable for persons outside of the discipline (Cheung, 2018). Researchers may be required to write lay summaries or media reports of their work, but all too often these are poorly done—almost to the level of disrespecting the very people they might be trying to reach. In this case study, we present a simple framework for writing about your research in a way that will help you to reach a wider audience.

The Science and Technology for Aging Research (STAR) Institute at Simon Fraser University is committed to turning great research into real-world products and services. A particular role of STAR is to help the research community to articulate and communicate its research to a wider community. The focus is on producing accessible written documents to be used in different ways, such as for newspaper articles, blogs, social media, etc. Knowledge mobilization and effective communications are covered in Chaps. 47 and 35, respectively, and this case study should be used in conjunction with those chapters. Some key ideas to consider:

- Avoid jargon and overly *academic* style of writing.
- Assume the reader is not familiar with your disciplinary concepts and language.
- The tone should be less formal than usual academic writing (i.e., engaging and easy-to-read but still *serious*).
- Briefing documents should be short and to the point.

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The STAR Institute has developed some simple guidelines and templates to help researchers summarize and communicate their ideas at different steps of the research. This is explained in terms of the five stages of our Product Innovation Pathway (PIP) model (PIP 1, Innovative Ideas; PIP 2, Planning; PIP 3, Development; PIP 4, Testing in Real-World Environment; PIP 5, Outcomes and Impact):

PIP Stage 1: Generating ideas—It is useful to summarize the current state-of-the-art research in an *information sheet*. This will provide the general reader with a simple “What we know” or “How to” guide to current knowledge on a research topic or area. These may include results from systematic reviews, rapid reviews, scoping reviews, etc., but may also include summaries of key information sources.

PIP Stage 2: Forming a project—A new research project can be summarized in a *project briefing*. This would be the lay summary of the who, what, why, how, where, and when of a new project that is typically required by funders. Your research briefing will provide an overview of the aims, objectives, and approaches of a research project. Projects here refer to any academic research that aims to produce outputs such as new knowledge, devices, or systems. This may include systematic reviews, rapid reviews, scoping reviews, results of trials, and others.

PIP Stage 3: Developing your product—As a project progresses in terms of tangible milestones and outputs, it is useful to communicate these through *research briefing notes*. These will present results of a research project. Projects here refer to any academic research that has produced outputs such as new knowledge, devices, or systems.

PIP Stage 4: Showing that it can work in the real world—This is a crucial step in the knowledge mobilization process. A *policy brief* will present an overview or results of a research project along with recommendations for action by a political body (e.g., ministry, service provider, nongovernment organization). A *business brief* will summarize how results of research could be developed into new business opportunities (e.g., via partner, start-up, or open source) for both profit and not-for-profit sectors. The business brief can highlight key market opportunities or may make specific recommendations for commercial or business development.

PIP Stage 5: Making an impact—Developing *impact case studies* using qualitative and/or quantitative data and metrics can make a powerful case for adoption. The case study will present a concrete example of how a research project and its findings have contributed to real-world impact:

- Social benefits—such as improved health, well-being, better services.
- Economic benefits—such as reduced costs, new jobs and businesses.
- Benefits local communities or across nations—anything that has particular relevance (e.g., establishing new international linkages).

Detailed guidelines and standard templates for the various briefing notes can be found at the Science and Technology for Aging Research (STAR) Institute website: http://www.sfu.ca/starinstitute.html.

Key Messages

- Academic articles are often incomprehensible to non-expert readers.
- Researchers need to articulate and communicate their research if they want to have social and economic benefits.

Funding Funding for this work was provided through Simon Fraser University Community Trust Endowment Fund (CTEF) via the Point of Care Health Technologies (PCHT) project (http://www.sfu.ca/pcht.html).

Reference

Cheung, I. (2018). Plain-language summaries: a vital ingredient in knowledge translation. https://www.msfhr.org/news/blog-posts/plain-language-summaries.

Chapter 38
Learning Activity: Getting Started Pitching Your Innovation

Richard McAloney and Leo Mui

The Challenge

The commercialization process involves taking ideas and research all the way through to a final product that customers can purchase. The reality is that this process is long and arduous where many technologies fail to make it to the end. The ability to effectively communicate the vision and the opportunity that awaits can dramatically improve the chance of success. Early in the Product Innovation Pathway (PIP), you are likely presenting and writing in academic settings. As you progress through the PIP, you will need to transition your communication skills to reflect the business side of getting your solution to market. This is often a challenge for researchers as the vocabulary, material, and level of information can feel like a foreign language. To ease into this transition, it helps to start building a pitch presentation early and to gather intelligence on the customer and what might be a sustainable business model.

Overview of the Activity

For entrepreneurs in startups, *life's a pitch*. You must transition from *science talk* to more engaging and general terms with a focus on more business-oriented content because part of your job will be to garner interest from stakeholders and investors. Developing a great pitch can be incredibly rewarding, as you will see people's

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bewildered looks turn into enthusiastic engagement. There's little doubt that you could describe your research in detail and explain how incredible your health technology is. However, as you move through the PIP, you will have to learn to articulate the value proposition, market size, business model, and other concepts pertaining to the opportunity and impact of your vision—and often to a lay audience. The aim of this activity is to provide a framework to help you start to build your pitch deck. A great pitch takes time and work; after completing this activity, you must continue to iterate and add information to refine the story you are telling. Continue to practice your pitch and gain insight from feedback from friends, colleagues, and advisors. Record yourself pitching on video and watch yourself. Critique your own presentation. Find slide deck examples, watch videos of others pitching, and attend start-up pitch competitions to pick up effective techniques and to learn which ineffective ones you should avoid.

Doing the Activity

In this activity, you will build the skeleton of a slide presentation about your emerging company.

Instructions for activity:

1. Read the content descriptions and presentation tips for each slide.
2. Lay out 20 sticky notes, a pair for each of your slides. Write a short title for each slide.
3. Spend 2 min writing bullet points for the key message(s) you want to deliver on one sticky note, and then spend another 2 min sketching out the slide layout (graphics, charts, word placement, etc.).
4. Complete step 3 for each slide. Skip the slides for which you don't yet have content.
5. This is a storyboard. Now reconsider the flow and order to tell the story better.
6. Begin building your slide deck.

Slide 1: Title

Keep it simple with your company name or logo and possibly a tag line type of statement. This is the first thing people will see so make it a good first impression. For your opening, the goal is to pique the interest of the audience so they want to continue to listen.

Slide 2: Problem

Describe the *pain* that you're alleviating. Don't go overboard if the problem is clearly understandable. As part of your pitch's opening, sometimes it is effective to use a personal story that describes your passion and why you targeted this problem—your audience should be able to relate.

Slide 3: Solution

Describe your product or service, but there is no need to go into technical details. Use only as much detail as you find necessary to make people believe your solution is viable. You must clearly convey what you sell and why the customer would value it. If you have patents for the technology, highlight this.

Slides 4–6: Opportunity

These slides should highlight the overall market opportunity and how you can build a sustainable business. It contains the size of the market, business model, who the buyer is (if it is different than the end user), and how you plan to reach them. Demonstrate that you understand your customer segment(s) and the proposed value proposition.

Market size can be calculated using bottom-up analysis of the market answering questions like how many people have the condition, how many long-term care homes, etc. You can reference secondary research such as market reports for the top-down analysis or your primary market research from customer interaction once you develop it. The business model demonstrates how you make money, and the business model canvas is an excellent development tool.

Slide 7: Competitive Analysis

Having competition is a good thing! In this slide, use a simple graphical or tabular analysis of competitive products and how you compare (favorably) to them on various factors. Show that you know your competition well, and never speak negatively about them.

Slide 8: Team

Convince the audience that you have what it takes to execute on your plan. Tie in the business and/or technical experience and credentials of each team member to their role. Establishing an advisory board is a great way to fill in any gaps.

Slide 9: Accomplishments and Plans

Show what you’ve done to date and how have you validated your assumptions. Proof of market traction or customer interaction is incredibly convincing. Provide milestones to highlight the important steps for the near future (resources required, regulatory steps, clinical trials, intellectual property [IP], etc.).

Slide 10: Closing the Presentation

Don't end abruptly with just saying: "Thanks, any questions?" Leave your audience with a takeaway that they won't forget. If you've opened with a relatable story, loop back to what you said in the opening. Repeat key ideas to emphasize what to remember about you.

Tips for the pitch deck:

- Limit your words.
- Use effective graphics.
- Aim for one key message per slide.
- 24-Point font minimum.
- Limit number of fonts.

Tips for pitch delivery:

- Practice delivery often.
- Memorizing opening lines helps manage nerves.
- Be enthusiastic.
- Record yourself and watch.

Learning Outcomes

- A storyboard for the overall message about the commercialization opportunity for your technology.
- A draft pitch presentation for your company.
- Identification of what content requires further research.
- An understanding of the content and delivery methods required to transition your mind set from science presentations to pitching the opportunity and impact of your company.

Learning More

- Kawasaki, G. (2014). *The art of the start: The time-tested, battle-hardened guide for anyone starting anything*. New York: Portfolio.
- Beckett, D. (2018). *Pitch to win*. Deventer: Vakmedianet Management.
- Osterwalder, A., & Pigneur, Y. (2010). *Business model generation: A handbook for visionaries, game changers, and challengers*. New Jersey: John Wiley & Sons.
- Duarte, N. (2008). *Slide:ology: the art and science of creating great presentations*. Sebastopol: O'Reilly Media.

Chapter 39
Informing Policy Through Partnerships

Dorina Simeonov, Candice Pollack, and Jenna Roddick

> *Policy making as we have known it is essentially a search for the best ideas—even the "right" idea—to solve a problem or achieve a public goal. Good policy work requires clear thinking, expert knowledge, and keen political judgement on trade-offs and compromises.*
>
> —Don Lenihan (2009)

The Challenge

Research is not meant to sit on a shelf. The aim of research is to create new knowledge to enable individuals, institutions, communities, and societies to make informed decisions that will have a positive impact on the world we live in. However, studies have found that there is a delay between the time that research results are published and their implementation. In a study by Morris, Wooding, and Grant (2011), for example, it was found that across 23 studies on average, the implementation of research findings into practice takes up to 17 years. This suggests that by the time people begin to use research findings as part of their decision-making processes, the opportunity for being forward-thinking and innovative has likely already passed. The challenge of translating scientific evidence into practice is especially important at the level of public policy as governments are working daily to develop modern solutions to address complex socioeconomic issues.

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Improving the speed and uptake of evidence into public policy are challenges that require concerted effort by researchers and policy makers. This chapter focuses on providing researchers with the tools they need to promote evidence-informed decision-making.

Key Ideas

The key ideas that will be addressed are:

- The policy development process wherein Canada serves as an example. In this process the right time and place for researchers to put forward evidence-informed interventions are detailed.
- How to build collaborative partnerships with policy and decision-makers to engage in evidence-informed decision-making.
- Tools that can be used to get scientific evidence in front of policy makers, their advisors, and into the public policy development process.

Understanding the Time and Place for Evidence-Informed Interventions in the Public Policy Development Process

Government policy development typically happens behind closed doors (Lenihan, 2009). Nevertheless, there are several ways for researchers to influence the policy making process. There are three main steps common to every government's policy system: (1) defining the problem, (2) developing policy options, and (3) recommending and implementing a solution (Lenihan, 2009).

Defining the Problem

At the federal level in Canada, policy priorities are identified by the Prime Minister's Office and the Privy Council Office (Townsend & Kunimoto, 2009) and then handed over to policy advisors from the relevant government departments to further define each challenge to be addressed. Policy advisors will scope out and analyze the problem they have been presented with thorough jurisdictional scans; informal dialogue with peers from other provinces, territories, or countries; and consultation with end users and external stakeholders (Townsend & Kunimoto, 2009). This is a key point where interventions from researchers are possible. While connections to decision-makers or influential interest groups with media coverage support may help get an issue on the political agenda as "the bureaucracy is [often] where it happens" (Voluntary Sector Initiative, 2003, p. 11), it is also critical to ensure that the scope of a policy challenge is properly defined and supported by research evidence. This is as important as ensuring the solution is evidence-informed.

Developing Policy Options

At this stage, policy advisors generate potential policy options through research on solutions implemented in other jurisdictions, those identified in the academic literature, and/or proposed by external parties such as contracted experts, advocacy groups, private organizations, and through public consultation. This is the second key space for intervention in policy making as policy advisors are generally interested in receiving information that will assist them with their task (Morestin, 2017). This process is iterative and dynamic (Farag, 2003; Lomas, 2000), characterized by many rounds of feedback and revision. Therefore the stronger the supporting evidence, the easier it is to justify a policy option to a deputy minister (see the Case Study).

Recommendation and Implementation

The last step is to provide a policy brief to the deputy ministers. This will usually include a summary of available options, the benefits and disadvantages of each choice, a cost-benefit analysis, and a sufficient amount of evidence for a recommended approach and decision to be made (Farag, 2003). The deputy ministers will then brief the minister(s) responsible for the file, who will make a decision to bring forward the recommendation to the Cabinet for authorization. While the brief provided by the policy advisor may be laden with scientific evidence, the minister responsible will base the decision within the wider environment of the respective political institution by balancing the political will for the decision, external stakeholder and interest group needs, and public opinion (Andrews, 2017; Boase, 1996).

Many factors play a role in government decision-making including internal politics, external politics, elections, media and public perceptions, competing agendas, personal bias, and allocation of resources with each carrying a different degree of influence in a given situation (Andrews, 2017; Kroeger, 1996; Lomas, Culyer, McCutcheon, McAuley, & Law, 2005). For example, the 2014 federal policy decision to allow income splitting for Canadians catered to public opinion rather than reflecting scientific evidence. While both the C. D. Howe Institute and the Broadbent Institute estimated that 85% of Canadian families would not benefit at all from an income splitting scheme, the federal government moved forward with implementation due to public support from key stakeholder groups (Béland, Laforest, & Wallner, 2014; Laurin & Rhys Kesselman, 2011). Accordingly, the contribution of scientific evidence to a particular decision will vary, and researchers looking to incorporate their research evidence into informing Canadian policy development should consider ways to influence the broader policy environment as well.

Overall, policy change at the legislative level can take decades and requires a combination of timing, available evidence, and partnerships for success. As a result, policy change is often incremental and needs to be evaluated and monitored along the way in order to achieve a broad and a long-term impact (Hutchinson, Abelson, & Lavis, 2001). However, change can start at the local level before it is made at a national level (see Case Study).

In summary, the key opportunities for intervention by researchers seeking to promote evidence-informed decision-making during the policy process are:

- At the problem identification stage, by assisting policy advisors to properly scope out the issue at hand.
- At the policy options development stage, by providing policy advisors with evidence to inform viable alternatives for solving the policy issue.
- Within the greater political process, by influencing the authorizing environment in which ministers operate.

Building Ongoing Partnerships Between Researchers and Policy Makers

Good evidence does not always make its way into a policy decision. There are cases in which policy is created in the absence of evidence and other cases where policy problems exist for which there is no established evidence base (Andermann et al., 2016; Supplee & Metz, 2014). One important factor in connecting policy and research is the creation of research-policy partnerships. These partnerships are ongoing, collaborative, and consistent interactions between a specific ministry, branch, or individual within government and, on the academic side, a specific research group, network, or institution (Richards, 2017).

Even though researchers and policy makers often have different goals, there can be short-term and long-term benefits to working together. In the short term, establishing partnerships provides the following benefits:

- Access to the latest published research or mutual sharing of raw data sets that help address a policy challenge.
- Interpretation or summary of the latest research by experts in the field for more relevant and accessible use by policy makers.
- Better use of time by policy advisors who are typically generalists.
- Increased knowledge and understanding among both researchers and policy makers about a particular policy issue and the state of the evidence on that issue.
- Resources for collaborative projects and events (e.g., researchers may have access to space in universities to host workshops or conferences) (Richards, 2017).

Over time, trust is built within a research-policy partnership resulting in opportunities for researchers to contribute in specific ways to the policy process. For example, researchers may be asked to review government reports or policies that are not yet available to the public. This allows researchers to provide valuable input and feedback on a particular challenge as policy documents are being developed by advisors or legislators.

Another example is the ability of researchers to convene stakeholders in a neutral environment to get their opinion, where it may be difficult for policy makers to do so depending on the policy issue. Researchers can support government initiatives by connecting them with industry, community organizations, and other interest groups to increase awareness of government projects, to create buy-in for future policy change, or to include new information in the policy process (Richards, 2017).

Further, there are key policy influencers, such as national organizations, that are well established and linked with government that researchers can join or engage with on policy challenges they are interested in solving using their findings. Coalitions of organizations, researchers, and members of the public affected by the issue all provide unique sources of evidence that are considered by policy makers. Deliberating this evidence among scientific and stakeholder communities can lead to consensus on the appropriate, feasible, and realistic policy options to move forward (Lomas et al., 2005).

Consider these key questions to ask yourself as you work toward establishing research-policy partnerships (Morestin, 2017):

- What type(s) of advisors do you need to contact? Do they need to have a technical or political background or that of a generalist or specialist?
- Do the advisors have a professional background that makes them familiar with the scientific knowledge you want to share or will you have to adapt your speech and writing when communicating with them? (See Chap. 35)
- How will the research you want to share help policy advisors with their tasks? Are the policy objectives of the advisors you are hoping to engage with aligned with the research you want to share?
- Have you considered the risks of sharing scientific knowledge with policy advisors? For example, that shared knowledge might be used as part of a political debate; and at what stage in the policy development process can your research inform policy advisors?

Box 39.1 The AGE-WELL National Innovation Hub in New Brunswick
AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence), Canada's national Network of Centres of Excellence focuses on technology and aging. It took a new approach to getting their research in front of policy makers. They established a national innovation hub with a focus on Advancing Policies and Practices in Technology and Aging (APPTA). The APPTA Hub exists to support government in generating opportunities to address the policy and practice challenges of an aging population by:

- Bridging the knowledge translation gap through connecting researchers and policy makers in the development of innovative solutions.
- Creating opportunities for knowledge exchange between Canadian jurisdictions.

(continued)

Box 39.1 (continued)

- Fostering an environment of innovation and collaboration in aging research and policy.

In short, APPTA builds sustained, meaningful relationships with both researchers in the AGE-WELL network and policy advisors with an aging, technology, or innovation portfolio so as to create more capacity for evidence-informed decision-making in aging policy and practice.

How do they do it?
The APPTA Hub has a dedicated internal capacity and a budget specifically for stakeholder relations. This is important, as it allows for ongoing engagement and an identified point of contact from which both research and government partners are able to connect and work. The key activities of APPTA that foster evidence-informed decision-making are:

- Translating research into evidence-informed solutions to address complex policy challenges in an accessible manner for government partners.
- Giving workshops for researchers and policy advisors to further develop their skills in policy engagement and knowledge translation (e.g., APPTA delivers workshops to graduate researchers on giving presentations to policy makers).
- Organizing annual in person meetings with policy advisors and decision-makers to promote knowledge exchange among Canadian jurisdictions.
- Building an integrated network of researchers and policy advisors by way of targeted communications formed through a needs-based assessment.

Developing Capacity with the Tools That Can Be Used to Get Scientific Evidence into the Public Policy Development Process

To avoid the unfortunate result of practical and potentially useful research not being utilized, it is important for researchers to learn how to present their work in ways that engage those who are able to implement and adopt that work as evidence-informed solutions. One way of doing this is in crafting a policy brief. A policy brief is a stand-alone document, typically between two and four pages, that presents findings and recommendations from research (Wong, Green, Bazemore, & Miller, 2017). This supports government in evidence-informed decision-making to create change in policy, as it relays evidence-informed solutions in a form that policy makers will read. When creating a policy brief, it is important to identify the specific policy actors to target (i.e., local or national) to ensure the brief reflects the level of application.

Box 39.2 provides a general template on how to create a policy brief to present research and evidence-informed solutions to government (Simeonov, 2018).

Box 39.2 Policy Brief Template

Issue	State the issue, what decisions need to be made, or what the is the research question surrounding the issue.
Current status	Provide current perspectives on the issue and what is being done at present to address it. Describe why this issue is of interest to the ministry and/or government.
Background	Provide a brief history of the issue and a rationale for who it affects. Describe what is known and unknown about the issue and possible responses using research evidence.
Key findings	Discuss the research conducted and its results in one to two sentences.
Policy recommendations	Provide recommendations to pursue. Provide a rationale addressing advantages and disadvantages of the recommendations. If appropriate, list possible actions that decision-makers and others can take based on current evidence. Discuss stakeholder impact or feedback. Examine possible sources of risk and mitigation, if any. Are there safeguards required for the appropriate implementation of the policy recommendation? For example, recommending the creation of a data registry and the costs and risks related to doing so.

Presenting research findings to policy makers and nonspecialists can be a challenging task for researchers. Suggestions for bringing your research and recommendations to the table include:

- Oral presentations:
  - Use the policy brief as a guide to the presentation.
  - Keep the methods short, and focus on the issue, results, and recommendations.
  - Identify the key message, and prepare an elevator pitch (see Chap. 35).
- Cost-benefit analyses:
  - Business case for implementing research.
  - Highlight the cost-benefit of adopting new evidence-informed policies.
  - Having the results of the cost-benefit analysis may be what sets the research apart from other proposals, as it provides a clearer insight into what the policy implementation would look like.

Product Innovation Pathway (PIP) Model

Informing policy change is a dynamic and ongoing process. Some of the activities listed below may happen throughout all stages, and researchers may need to go through multiple cycles of the PIP model when working with policy makers given the fast pace in which policy priorities can shift. Still, there are key activities that are aligned with this model when it comes to engaging government (see Table 39.1).

Finding Support
Talk to your research or community partners that are already engaging with government in your field. Your organization or home institution may also have someone who is designated in the role of working in government or partnership relations. This individual may be able to provide an introduction to key policy advisors or policy makers. Visit your government's website; it may have specific instructions on how to submit a policy brief or other submission for consideration. Below are key resources for further reading:

- Theresa McKeown & Associates. (2009). "How to" manuals. https://www.publicsectorwriting.com/?page_id=25.
- Morestin, F. (2017). *Policy makers' advisors, scientific knowledge and knowledge sharing: Highlights of a literature review and key lessons.* Montreal: National Collaborating Centre for Healthy Public Policy. http://www.ncchpp.ca/docs/2017_PC-KS_ConseillersAdvisors_resume_EN.pdf.

Table 39.1 Product Innovation Pathway (PIP) model—informing policy through partnerships

PIP level	PIP description	Key activities
1	Policy ideas	Connect with existing partners with government connections; discuss benefits of research-policy partnerships; develop a partnership plan. Ask yourself—who will you target at what level of government? Discuss current policy issues on the agenda; inform policy issues with existing scientific evidence; create a plan for ongoing communication; write policy briefs; create presentations.
2	Planning	Develop policy options that are informed by scientific evidence; include cost-benefit analysis when possible; examine what other jurisdictions are doing to address this policy issue; host joint meetings to improve everyone's understanding of the policy climate and state of the evidence on the issue; refine policy briefs.
3	Development	Consult stakeholders on the policy options; engage members of the public, community organizations, and industry partners that are concerned about the issue; inform the broader set of stakeholders about the policy climate and state of the evidence; assess or build buy-in for policy options; establish coalitions on the issue.
4	Testing in real-world environment	Pilot policy idea, project or program; monitor change after implementing the policy idea; evaluate effectiveness; refine details; seek feedback from broader stakeholder group.
5	Outcomes and impact	Make recommendation for policy change; work with policy makers to legislate policy; evaluate and review policy; work with broader stakeholders to implement policy.

Key Messages

Engaged researchers need to understand the broader policy process within which their research can contribute to real-world impact. They need to adopt an approach to engaging policy makers and policy advisors. These approaches can include:

- Building strong partnerships through collaborating on specific policy issues or projects.
- Using plain language, policy briefs, and regular communication to share findings.
- Providing connections to other key interest groups and the public related to a specific policy issue as well as the latest published evidence and expert opinion.

References

Andrews, L. (2017). How can we demonstrate the public value of evidence-based policy making when government ministers declare that the people "Have had enough of experts"? *Palgrave Communications, 3*(Article 11).

Béland, D., Laforest, R., & Wallner, J. (2014). Canada's worst policy ideas of 2014. In due course: a Canadian public affairs blog [Blog post]. http://induecourse.ca/canadas-worst-policy-ideas-of-2014/.

Boase, J. P. (1996). Institutions, institutionalized networks and policy choices: Health policy in the US and Canada. *GOVE Governance, 9*(3), 287–310.

Farag, M. (2003). *A guide to policy development*. Winnipeg: Office of the Auditor General Manitoba (January). https://www.oag.mb.ca/wp-content/uploads/2011/06/PolicyDevelopmentGuide.pdf.

Hutchinson, B., Abelson, J., & Lavis, J. (2001). Primary care in Canada: So much innovation, so little change. *Health Affairs, 20*(3), 116–131.

Kroeger, A. (1996). A retrospective on policy development in Ottawa. *Canadian Public Administration, 39*(4), 457–468. https://doi.org/10.1111/j.1754-7121.1996.tb00145.x

Laurin, A., & Rhys Kesselman, J. (2011). *Income splitting for two-parent families: Who gains, who doesn't, and at what cost?* (Report no. 335). Toronto: C. D. Howe Institute. https://www.cdhowe.org/sites/default/files/attachments/research_papers/mixed/Commentary_335.pdf.

Lenihan, D. (2009). *Rethinking the public policy process: A public engagement framework*. Ottawa: Public Policy Forum. http://canada2020.ca/wp-content/uploads/2015/05/FRAMEWORK-PAPER-.pdf.

Lomas, J. (2000). Connecting research and policy. *Canadian Journal of Policy Research, 1*(1), 140–141.

Lomas, J., Culyer, T., McCutcheon, C., McAuley, L., & Law, S. (2005). *Conceptualizing and combining evidence for health system guidance*. Ottawa: Canadian Health Services Research Foundation. http://www.cfhi-fcass.ca/migrated/pdf/insightAction/evidence_e.pdf.

Morestin, F. (2017). *Policy makers' advisors, scientific knowledge and knowledge sharing: Highlights of a literature review and key lessons*. Montreal: National Collaborating Centre for Healthy Public Policy. http://www.ncchpp.ca/docs/2017_PC-KS_ConseillersAdvisors_resume_EN.pdf.

Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: Understanding time lags in translational research. *Journal of the Royal Society of Medicine, 104*(12), 510–520. https://doi.org/10.1258/jrsm.2011.110180

Richards, G. W. (2017). How research-policy partnerships can benefit government: A win–win for evidence-based policy-making. *Canadian Public Policy, 43*(2), 165–170. https://doi.org/10.3138/cpp.2016-046

Simeonov, D. (2018, September 15). Personal communication.

Supplee, L. H., & Metz, A. (2014). Opportunities and challenges in evidence-based social policy. *Social Policy Report, 28*(4), 1–16. https://eric.ed.gov/?id=ED566688.

Townsend, T., & Kunimoto, B. (2009). *Capacity, collaboration and culture: The future of the policy research function in the Government of Canada (March)*. Ottawa: Policy Research Initiative.

Voluntary Sector Initiative. (2003). *Participating in federal public policy: A guide for the voluntary sector (October)*. Ottawa: Government of Canada. http://sectorsource.ca/sites/default/files/policy_guide.pdf.

Wong, S. L., Green, L. A., Bazemore, A. W., & Miller, B. F. (2017). How to write a health policy brief. *Families, Systems & Health, 35*(1), 21–24.

Chapter 40
Case Study: From Stakeholder Engagement to Policy Change—Lessons from Alberta's Bill 210, the Missing Persons Amendment Act (Silver Alert)

Lili Liu, Noelannah Neubauer, and Christine Daum

The Challenge

Three out of five persons with dementia wander and get lost (Alzheimer's Association, 2016). The search for missing persons is costly (Sharples, 2009), and the incidence of missing older adults with dementia continues to rise with population aging. Whereas 5% of previous search and rescue cases for missing persons involved older adults, this is now nearly 50% of cases (Neubauer, Laquian, Conway, & Liu, 2018). If not found within 24 hours, up to half of those lost will sustain serious injury or death (Alzheimer's Association, 2016), a major concern for first responders and caregivers alike (Neubauer, Hillier, Conway, Beleno, & Liu, 2018). Currently, there is a petition for a Canadian National Silver Alert strategy that cites Alberta and Manitoba as the only provinces that "established a Silver Alert, through an amendment to their *Missing Persons Amendment Act*" (House of Commons, 2018). This case study describes our experience in amending Alberta legislation and presents cautions about the national petition.

The Community ASAP was funded by AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence), Canada's Technology and Aging Network, and the Centre for Aging and Brain Health Innovation (CABHI). Dr. Lili Liu and her team were approached by Carya (formerly Calgary Family Services) to engage in a private members' bill to amend Bill 210, the Missing Persons Act. Mark Smith, a member of the Alberta Legislative Assembly for Drayton Valley-Devon, initiated the amendment of Bill 210 to include a Silver Alert section. The new legislation allows any police service in Alberta to send a *silver alert* using a messaging system

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that disseminates information to the public through local media and smartphone notifications. A similar amendment was passed in Manitoba earlier (Bill 214: the Missing Persons Amendment Act [Silver Alert]). Dr. Liu prepared a brief on the range of silver alert systems, and associated research, to Mr. Smith. Dr. Liu and Ph.D. student Neubauer attended the second and third reading of the bill to understand the culture of the legislative assembly. The private member's bill was passed with unanimous consent from both sides of the Legislative Assembly.

Dr. Liu's team provided research evidence and guidance to inform the operationalization of the amended Bill 210. Dr. Liu conducted telephone consultations, prepared a literature review, and presented at the Standing Committee on Families and Communities panel. Her presentation included these elements:

- Demographics on persons living with dementia at risk of wandering.
- The limited evidence supporting a generalized public alert system resembling an amber alert.
- Current challenges locating and keeping vulnerable older adults safe within their communities.
- Recommendations to improve processes and supports.

Dr. Liu argued that evidence from the United States suggests that the government-funded alert system is limited because states differ in age categories of older adults that qualify for an alert and procedures vary across geographical boundaries. Her team encourages that people *avoid* associating a silver alert with an amber alert. Unlike a silver alert, an amber alert is:

- Typically associated with a criminal activity (abduction).
- Seldom triggered.
- Covering a wide geographic area.

Unless detained under the Mental Health Act, or legally under the care of another person, older adults have a right to go missing. If a generalized alert is triggered every time an older adult is missing, a community would quickly experience alert fatigue.

Rather than a widespread media alert, as in an amber alert, Liu's team is advocating for multiple options. One option is the Community ASAP, an opt-in system, an app that notifies community members when a vulnerable older adult is missing in the vicinity. Community members serve as extra eyes on the ground to recognize a missing person and report the location of the missing person to first responders. The role of community volunteers is *not* to search and rescue.

To achieve Level 5 of the Product Innovation Pathway, Dr. Liu and her team worked with key stakeholders, for example, end users, police, community organizations, and municipal government, to design C-ASAP and enable clear and cohesive communication with decision-makers. Active listening to stakeholders is essential, followed by timely actions to demonstrate that stakeholder recommendations are implemented. Through this process, trust and credibility are generated.

Outcomes and Impact

The work described instilled real-world impact in several ways. Our briefs provided government with evidence used to deliberate the passing of Alberta's Bill 210. The research outcomes resulted in a press release, television and newspaper interviews, and Web stories on partner organization websites, which may have influenced the policy climate. Relationships were developed that facilitated collaboration on other future initiatives. The team delivered a workshop at a national gerontology conference attended by health and social care providers and policy influencers as well as senior advocates. This workshop became an example of how stakeholders can organize to effect policy change.

Alberta's (and Manitoba's) amendment to the Missing Persons Act to include a *silver alert* can be misleading because it highlights vulnerable older adults in an act that previously focused on missing children (amber alert). The amendment is in no way a *silver alert strategy*. Indeed, *silver alert* strategies are different from amber alert protocols.

Key Messages
- Stakeholder engagement is necessary for legislative change.
- Translation of research evidence to inform policy must align with politicians' priorities and remain nonpartisan.
- Researchers must be focused and persistent in enforcing key messages that help decision- and policy-makers understand the implications of their decisions.

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References

Alzheimer's Association. (2016). *2016 Alzheimer's Disease facts and figures report*. http://www.alz.org/facts/.

House of Commons (Canada). (2018). *E-1588 (ELDERLY)*. https://petitions.ourcommons.ca/en/Petition/Details?Petition=e-1588.

Neubauer, N., Hillier, L. M., Conway, C., Beleno, R., & Liu, L. (2018). Reflections of the use of locating technologies with persons with dementia: Proceedings of a key stakeholder forum. *Neurodegenerative Disease Management, 8*(3), 195–205.

Neubauer, N., Laquian, K., Conway, C., & Liu, L. (2018). *Development of a guideline of best police practices in locating lost persons with dementia*. Canada: Mitacs.

Sharples, T. (2009, April 25). Get into trouble outdoors—Who pays for the rescue? *Time Magazine*. http://content.time.com/time/nation/article/0,8599,1892621,00.html.

Chapter 41
Navigating Policy, Regulatory, and Health System Landscapes

Maggie MacNeil, Don Juzwishin, and Paul Stolee

The Challenge

New technologies, services, and products can help people live healthier lives, but innovators often struggle to get their solutions in the hands of people, their families, and the systems that help to care for them. Technologies exist to help healthcare institutions, individuals, and caregivers to manage health and well-being, but the layers of jurisdiction combined with silos across types and levels of care settings are complex for innovators to negotiate. Innovations that are developed without an understanding of, or partnership with, the health system can miss out on access to patient groups, clinicians, expert advice, or real-world settings to pilot their technology and make a significant health impact. Existing policies and regulation were introduced in response to a need to protect the public interest, but these were solutions to problems of the past. Times and technologies change, thereby rendering some policies and regulations outdated. This can pose a significant challenge to innovations. Innovators need to recognize and understand health systems and the accompanying sets of policies and regulations in order to facilitate the adoption process. This chapter outlines policies and regulations that complicate the process of bringing a health innovation to market in Canada; these issues are also relevant to other healthcare contexts.

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Key Ideas

Engaging Stakeholders and End Users from the Start

Given the many different stakeholders involved in healthcare design, healthcare delivery, and health innovation, there are many perspectives to consider when beginning to develop or adapt a new solution or new product. The *end user* can be a healthcare professional, or it can be a patient; the *payer* could be the individual, a caregiver, provincial government or a health authority, or some combination of the three. Innovators want their innovations to appeal to the people they will be used to help, the professionals who might help use them and fit the environment, whether used in private homes or healthcare settings. Co-design with end users and partnering with stakeholders (see Chap. 41) to understand their needs, perspectives, and values ensure the innovation is as relevant as possible and identifies key barriers to adoption. Innovators who wait too long to seek feedback from end users and stakeholders tend to overestimate the value of their ideas and solutions, make costly mistakes, and focus on empowering physicians, as opposed to patients or other care providers (Lehoux, Daudelin, Hivon, Miller, & Denis, 2014; Lehoux, Williams-Jones, Miller, Urbach, & Tailliez, 2008).

Understanding the Jurisdictional Landscape

The jurisdictional context in which a new technology, service, or practice is being introduced can be highly complex. In Canada, for example, there are multiple jurisdictions at different levels. The federal government is responsible for regulating drugs, medical devices, and technologies. However, provinces are responsible for delivering healthcare and social services. Some provinces, including British Columbia and New Brunswick, further *decentralize* healthcare responsibility to regional healthcare entities, where other provinces such as Alberta and Nova Scotia have a single healthcare governance and administration body (Marchildon, 2013). Different provinces have different models for how they pay for the healthcare services not covered by the Canada Health Act, such as pharma-care programs, home and community care services, and assistive technology programs (Marchildon, 2013). Different parts of the healthcare system (hospital, home care agency, rehabilitation sector, and long-term care home) have different capacities to test, evaluate, adopt, procure, and reimburse technologies. This results in different types of policies across healthcare settings, across provinces, and occasionally across different regions in the same province, making it difficult to introduce a promising idea or scale up a proven idea across Canada. For example, despite the increased need for assistive technologies created by aging demographics and the trend toward aging in place, a fragmented system with no clear entry point impedes patients' access to these technologies (Mattison, Wilson, Wang, & Waddell, 2017). Specifically, access is impeded by different definitions of assistive technology between provinces and between different funding entities within provinces (provincial, private insurance, not-for-profit) and varying eligibility criteria related to income levels (Mattison et al., 2017). This example demonstrates how reimbursement programs can reinforce the status quo and prevent disruptive innovation, which might offer a more affordable technology to an underserved portion of the market (Bhavan, Agrawal, & Cerise, 2016).

Standards

There are other regulatory requirements that innovators should be aware of to ensure end users that their product, and each of its parts, is safe and reliable (Chanda et al., 2016). The Canadian Standards Association (CSA) Group provides products with certification marks that provide consumers, retailers, and end users with certainty that the product has been independently tested and has met the required standards for safety and performance (CSA Group, 2018). In order to sell electrical and electronic products, gas-fired products, and many other products in North America, they must be approved by a third-party testing agency, such as the CSA Group. Certification is initiated by innovators contacting the CSA Group and providing information about their product. This information includes how and where it will be used; what countries it will be used in; marketing information about the product; a list of all the components and materials used; and contact information about the manufacturing company of the product.

Policy processes may differ for technologies based on their site of use. For example, a preventive, home-monitoring system could be relevant to the home and community care sector, which might have different adoption, financial capacity, and implementation challenges than a technology such as a magnetic resonance imaging (MRI) machine to be used in an acute care setting. Depending on what a technology will do (diagnose or prevent disease; restore bodily functioning; or use software to view images or determine measurements) and on how it is marketed (e.g., making specific health claims for a specific medical condition), it may be classified as a medical device, which requires regulation by Health Canada (Health Canada, 2012).

Regulation and Health Technology Assessment

Not all products used to promote the well-being of individuals will require regulation. If the device is not categorized as a medical device, it is not necessary to undergo the regulatory process. In addition, many medical devices and health technologies will not undergo a health technology assessment (HTA). HTAs are systematic evaluations of technologies using evidence to consider the direct and unintended costs and consequences of the technology (International Network of Agencies for Health Technology Assessment, 2006). If these phases are not undergone, the commercialization and marketing of the device may require greater efforts and resources at the expense of the innovators. For these devices, reimbursement will also be different. Third-party and private payers will have to be explored as a funding option. Many new innovators may decide to test the waters with their technology as a consumer device, refine it, and reintroduce it on the market as a medical device at a later point. It is the innovator's responsibility to understand how their technology's function and the language they use to market it will interact with the definition of a medical device. There are gray areas in legislation for new technologies that are software-enabled or for the many technologies which occupy the *health and wellness* space (Koch, 2017), for example, health apps. Innovators would be well-advised to reach out to regulators to learn more about how their technology would be processed, if it were considered a medical device. The Canadian Medical Association published a set of guidance for physicians recommending mobile apps to patients, which innovators can consult if they wish to have their technologies used for managing health conditions (see Box 41.1) (Canadian Medical Association, 2015).

Box 41.1 Guiding Principles for Physicians Recommending Mobile Health Applications to Patients

In 2015 the Canadian Medical Association (CMA) became the first national medical association to issue guidance for physicians on how to assess mobile health technologies to recommend to their patients. The CMA also created patient handouts to help patients decide whether to use an app to help manage health conditions. The principles include:

- Endorsement by a recognized professional organization such as the Canadian Medical Protective Association.
- Usability including recent updates by developers.
- Reliability of information: the physician has reviewed and is in agreement with the health information contained in the app.
- Privacy and security: the physician has outlined the risks associated with storing health information in a mobile phone and encouraged use of apps with standards of authentication such as passwords or encryption.
- Avoidance of conflict of interest: physician has outlined the possibility of the app development company selling the patients' health information or profiting in a secondary way from their use of the app.

Identifying Outcomes and Measurable Indicators of an Innovation

Traditionally, new health technologies and innovations such as medical devices undergo rigorous study to determine cost-effectiveness and clinical effectiveness through a HTA. Although resource and time constraints prevent every technology from undergoing a HTA, the HTA process can provide a framework to help innovators understand and demonstrate the value of their technology in a way that is meaningful to patients, end users, clinicians, and payers. Investment in new innovations in healthcare generally follows the triple aim philosophy: improving patient experience, improving population health, and reducing costs of healthcare (Berwick, Nolan, & Whittington, 2008). Innovators should consider:

1. What performance indicators have been chosen to provide rationale for the investment of (often taxpayer) dollars in this product?
2. Does this product make a difference in the efficiency of care delivery, effectiveness of clinical outcomes for patients, quality of life, reduction of length of stay in traditional institutions, and so on?
3. Healthcare leaders require data that can justify innovation expenditures. Are there available indicators that could be used to track the impact of the innovation (such as one of the interRAI™ standardized assessments, which are available through nationally reported datasets in the Canadian Institute of Health Information [CIHI]) (Hirdes et al., 1999, 2004)?
4. What stakeholder expertise could be sought out to help choose relevant indicators? Involving end users in identifying and selecting indicators can be time well spent.

Keeping the End in Sight: Finding a Market

The process of innovation consists of several overlapping, iterative, and interconnected phases. In order to facilitate smooth transitions through the innovation process, it is important to look ahead to the anticipated goal or outcome. Innovators in the early steps may want to consider the following:

- Would this technology qualify as a medical device? Why or why not?
- Is it a consumer device? Why or why not?
- Who is the target end user? Is it the patient? Family member? Healthcare provider?
- How will this device be marketed, and who will it be marketed to?
- How will end users inform co-development of the technology?
- Is there an effective commercialization advisory and business development team that can help inform how to deal with the legal and regulatory requirements

associated with report of invention, intellectual property (IP) filing and management? Business planning, marketing analysis?
- What reimbursement opportunities exist for this technology? Can risk be shared with private partners?

Answering these questions will help to determine what policies and regulations may be relevant to the innovation process.

Keeping the End in Sight: Integrating with the Healthcare System

Healthcare systems have been said to be change averse. Path dependency is the influence that past processes of government have on future trajectories of government and the ability of past processes to stall substantial change in the future (Brady, Marquardt, Gauchat, & Reynolds, 2016). An institutionalized path dependency in how care is delivered along with a general cost containment focus in healthcare exists, to the detriment of new innovations many of which require significant up-front investment in order to see value. Value may not be demonstrable within health system timelines, and it may appear in a different healthcare setting rather than in the setting which purchased the technology. For example, an in-home health monitoring system used by home care nurses might result in reduced admissions to emergency rooms; thus, the costs incurred in one sector thereby reap cost savings in another sector (Koch, 2017). Budgets between healthcare settings are typically siloed, and thus different settings resist spending on innovations that will incur savings to another setting. For example, the home care sector resists spending on an innovation that will benefit the bottom line of the acute care setting as opposed to its own bottom line. Often, financial allocations in healthcare are based on routine, historical precedent, or political factors (Baltussen & Niessen, 2006). This practice disadvantages innovative solutions working in underfunded sectors of the healthcare system such as home and community care. Additionally, resources are not easily redeployed among different sectors of the system or across fiscal years (Menon & Stafinski, 2009).

It may be easier for an innovator to approach jurisdictions that have:

- Value-based procurement calls, allowing for the consideration of value as opposed to the cost of a technology.
- Procurement processes that are open to industry, government, and healthcare provider risk sharing in the development of new innovations.
- A life cycle approach to health technology management, which includes evaluating existing procedures in order to reinvest in higher value alternatives or innovative reimbursement mechanisms that allow for the department that benefits from a technology to reimburse the department that purchased the technology (if they are not the same department) (Mullie, Osiowy, & Juzwishin, 2017).

Understanding Tradeoffs and Budgetary Reallocations in Healthcare

The gap between a good idea in healthcare and introducing it into practice can be separated by as many as 10–15 years (Balas & Boren, 2000). In today's reality of fiscal containment and rapidly evolving technologies, we must be much more adept at translating promising innovations to practice. The HTA community emphasizes the importance of evaluating health technologies over their life cycle, conducting ongoing evaluations, and delayering innovations and how these processes create budget flexibility to support adoption of new technologies and a more sustainable system over time (Keown et al. 2014). After implementation, technologies need reassessment to ensure they are still providing value for money and not being over prescribed.

Innovators should work with patients, healthcare providers, and leaders to think about how the innovation will impact clinical care, program pathways, and the impact on staff. Knowledge translation and implementation plans with budgetary implications and recommended solutions that are prepared for healthcare leaders can help expedite the process of introducing the innovation (Table 41.1).

Table 41.1 Product innovation pathway (PIP) model—navigating the policy, regulatory, and health system landscapes

PIP level	PIP description	Key activities
1	Innovative ideas	Identify key concepts, ideas, and knowledge gaps in terms of policy, regulatory, and reimbursement issues in Canada Explore a variety of methods Understand end users' and policy makers' needs
2	Planning	Decide on project methodology and project partners. Begin scoping the literature
3	Development	Use understanding from literature and from end users and project partners to begin to create resources Decide the order in which the resources will be most useful—are some more helpful for development while others are more suited to knowledge translation steps of the project?
4	Testing in real-world environment	Trial resources for innovators within a trusted group, move to trialing resources with a broader, more representative group Seek project partners' feedback on products Trial resources for policy makers with stakeholders, use policy products to stimulate discussion around the *wicked* policy problems, generate potential solutions
5	Outcomes and impact	Assess how resources have performed and how they need to evolve: What needs to be added? Is the information presented in a way that it is easily understood? What is still unknown? What resources (financial, human resource, time, expertise) are required to ensure optimal uptake?

Finding Support

- Information about medical devices can be found on this Government of Canada website: https://www.canada.ca/en/health-canada/services/drugs-health-products/medical-devices.html.
- The Canadian Institute for Health Information provides data about Canada's health system: https://www.cihi.ca/en/access-data-and-reports/make-a-data-request/data-holdings.
- PRI-TECH PRIMER: What health technology innovators should know. https://uwaterloo.ca/geriatric-health-systems-research-group/sites/ca.geriatric-health-systems-research-group/files/uploads/files/pritech_manual.ref_adjusted_accessible.pdf.

Key Messages

- The policy, regulatory, and reimbursement landscape in healthcare can be complex, messy, and varied across jurisdictions (i.e., federal, provincial, territorial).
- A common feature is that healthcare leaders are seeking ways to innovate healthcare delivery without a significant additional investment.
- Innovators have the opportunity to work with their providers, governments, industry, and their patients and clients to identify ways to co-develop innovations.

References

Balas, E. A., & Boren, S. A. (2000). Managing clinical knowledge for health care improvement. In J. Bemmel & A. T. McCray (Eds.), *Yearbook of medical informatics 2000: Patient centred systems* (pp. 65–70). Stuttgart: Schattauer Verlagsgesellschaft mbH.

Baltussen, R., & Niessen, L. (2006). Priority setting of health interventions: The need for multi-criteria decision analysis. *Cost Effectiveness and Resource Allocation, 4*(14), 1–9. https://doi.org/10.1186/1478-7547-4-14

Berwick, D. M., Nolan, T. W., & Whittington, J. (2008). The triple aim: Care, health, and cost. *Health Affairs, 27*(3), 759–769. https://doi.org/10.1377/hlthaff.27.3.759

Bhavan, K. P., Agrawal, D. A., & Cerise, F. (2016). Achieving the triple aim through disruptive innovations in self-care. *JAMA, 316*(20), 2081–2082. https://doi.org/10.1001/jama.2016.15391

Brady, D., Marquardt, S., Gauchat, G., & Reynolds, M. M. (2016). Path dependency and the politics of socialized health care. *Journal of Health Politics, Health Policy and Law, 41*(3), 355–392. https://doi.org/10.1215/03616878-3523946

Canadian Medical Association. (2015). *Guiding principles for physicians recommending mobile health applications for their patients*. Ottawa: Canadian Medical Association. https://www.cma.ca/Assets/assets-library/document/en/advocacy/cma_policy_guiding_principles_for_physicians_recommending_mobile_health_applications_to_patients_pd1-e.pdf.

Chanda, N., Kuspinar, A., MacNeil, M., Koch, M., Brooks, L., Papasideris, M., … Stolee, P. (2016). *PRI-TECH PRIMER: what health technology innovators should know*. Waterloo: University of Waterloo. https://uwaterloo.ca/geriatric-health-systems-research-group/sites/ca.geriatric-health-systems-research-group/files/uploads/files/pritech_manual.ref_adjusted_accessible.pdf.

CSA Group. (2018). *Canadian Standards Association Group*. http://www.csagroup.org.

Health Canada. (2012). Health Canada—Drugs and health products. https://www.canada.ca/en/health-canada/services/drugs-health-products.html.

Hirdes, J. P., Fries, B. E., Morris, J. N., Ikegami, N., Zimmerman, D., Dalby, D. M., … Jones, R. (2004). Home care quality indicators (HCQIs) based on the MDS-HC. *The Gerontologist, 44*(5), 665–679. https://doi.org/10.1093/geront/44.5.665

Hirdes, J. P., Fries, B. E., Morris, J. N., Steel, K., Mor, V., Frijters, D., … Jónsson, P. (1999). Integrated health information systems based on the RAI/MDS series of instruments. *Healthcare Management Forum, 12*(4), 30–40. https://doi.org/10.1016/S0840-4704(10)60164-0

International Network of Agencies for Health Technology Assessment (INAHTA). (2006). HTA glossary. http://htaglossary.net/HomePage.

Keown, O., Parston, G., Patel, H., Rennie, F., Saoud, F., Kuwari, H., & Darzi, A. (2014). Lessons from eight countries on diffusing innovation in health care. *Health Affairs, 33*(9), 1516–1522, https://doi.org/10.1377/hlthaff.2014.0382.

Koch, M. (2017). *Aging-related technologies: A multiple case study of innovation processes* (Master's thesis). University of Waterloo, Waterloo, Ontario, Canada. http://uwspace.uwaterloo.ca/bitstream/handle/10012/12418/Koch_Melissa.pdf?sequence=3&isAllowed=y.

Lehoux, P., Daudelin, G., Hivon, M., Miller, F. A., & Denis, J. L. (2014). How do values shape technology design? An exploration of what makes the pursuit of health and wealth legitimate in academic spin-offs. *Sociology Health Illness, 36*(5), 738–755. https://doi.org/10.1111/1467-9566.12097

Lehoux, P., Williams-Jones, B., Miller, F., Urbach, D., & Tailliez, S. (2008). What leads to better health care innovation? Arguments for an integrated policy-oriented research agenda. *Journal of Health Services Research and Policy, 13*(4), 251–254. https://doi.org/10.1258/jhsrp.2008.007173

Marchildon, G. (2013). Canada health system review. *Health Systems in Transition, 15*(1). http://www.euro.who.int/__data/assets/pdf_file/0011/181955/e96759.pdf.

Mattison, C., Wilson, M. G., Wang, R. H., & Waddell, K. (2017). *Evidence brief: enhancing equitable access to assistive technologies in Canada*. Hamilton: McMaster Health Forum. https://www.mcmasterforum.org/find-evidence/products/project/enhancing-equitable-access-to-assistive-technologies-in-canada.

Menon, D., & Stafinski, T. (2009). Health technology assessment in Canada: 20 years strong? *International Society for Pharmacoeconomics and Outcomes Research, 12*(Suppl. 2), S14–S19. https://doi.org/10.1111/j.1524-4733.2009.00554.x

Mullie, T., Osiowy, K., & Juzwishin, D. (2017). Making informed technology decisions: moving from "in principle" to "in practice" using the strategic decision making and resource allocation framework. Panel presentation at the Canadian Agency for Drugs and Technology in Health Symposium, Ottawa, ON. https://www.cadth.ca/sites/default/files/symp-2017/presentations/april25-2017/Concurrent-Session-D2-Thomas-Mullie.pdf.

Chapter 42
Commercializing Research Innovations: An Introduction for Researchers

Lupin Battersby and Pooja Viswanathan

The Challenge

Increasingly researchers are expected to demonstrate the real-world impact of their research. This is understandable given that research is predominantly funded with public dollars, is growing at an exponential rate, and is becoming more publicly accessible and therefore is under greater scrutiny. One of the crucial strategies for creating impact with research innovations is commercialization. For example, if a new health technology is to go beyond the pilot or demonstration phase, it has to be further refined, manufactured, and marketed, all of which requires monetary investment. This is increasingly important as digital health technologies and assistive devices are part of a growing direct-to-consumer health-care market. However, most people working in academic research fields are unprepared for the challenge of commercialization (see Mehta, 2004). In this chapter we will present some basic ideas, tools, and pointers to help researchers get started on commercialization of their research innovation. Concepts encompassed in this chapter include how to:

- Achieve a result you are happy with: licensing versus launching.
- Know who needs it: customer, market, and value proposition.
- Understand what you have: innovation, problem identification, and intellectual property.
- Get it to those who need it: value chain, partners, co-creation, adoption, and diffusion.

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- Find money to get it going: non dilutive, equity funding, and venture capital.
- Build a business model with the business model canvas: draft, validate, edit, and repeat.

Key Ideas

Achieving a Result You Are Happy with

Have the courage to know your own reason.
—Immanuel Kant, *Foundations of the metaphysics of morals*, 1785

Take a moment and consider the goal you want to achieve with this innovation. Do you want to ensure that the people who could benefit from the research innovation can access it? Do you want to become an entrepreneur? Perhaps you want to get back to your next research project as fast as possible, but feel compelled to do a little knowledge mobilization to meet your commitments to the grant funder? There is no right or wrong answer. However, there are different paths to take depending on your answer. Knowing this answer before you plan for the future of your research innovation will help you to achieve a result you are happy with.

The first fork in the path of commercializing a research innovation is to choose whether to license the intellectual property or launch a start-up. Technology can be licensed to an entrepreneur or company. Licensing fees and conditions need to be established, and then it is their responsibility to address all the other decision points. Augurex Life Science Corporation (Augurex) is a great Canadian example of this type of an agreement. A University of British Columbia researcher discovered a biomarker implicated in rheumatoid arthritis. Augurex founders licensed the discovery through the university innovation office and have developed a blood test for diagnostic purposes. They are now working on a number of other applications for this biomarker. This is an example of how innovation offices can be utilized in commercialization of research discoveries.

If you choose to take the start-up path, there will be many more forks in the road in terms of achieving a result with which you are happy. One question to ask yourself is whether you are the best person to the lead the company or should you bring in an expert? Further down the path, if you are moving along successfully, you may find that you need more capital and you may need to choose whether or not to become a publicly offered company. Another option is that you choose to be bought out by a larger company (most successful science-based start-ups are bought out within 12 years; see Maine, Lubik & Garnsey, 2012). If you know what you want for your innovation, you can achieve a result that satisfies you.

Either way, you should disclose your invention as early as possible to your technology transfer office. This will help clearly define and separate academic intellectual property (IP) from any future commercial IP, and it will allow time for licensing agreements to be drafted. However, before knowing what IP can, or should, be licensed, you will first need to understand your potential licensee's market landscape and what kind of competitive edge your innovation might offer.

Knowing Who Needs It and Who Benefits

To ascertain who needs your innovation, it is important to be clear on the problem that your innovation is solving. Is it a problem that actually needs solving? Who will use it versus who will benefit from it? To determine this you need to talk to people—do this now before you go any further. For example, let's say you want to create a new tablet for older adults that addresses a number of accessibility issues while it helps with problems such as social isolation as well as being user-friendly. Before you start, talk to your target population about their needs and lifestyles: How do you stay socially connected?; What technology do you use now to stay connected?; What works well about that technology?; What does not work well?; Would you use a tablet designed for older adults?; Why or why not?; What would be useful about it for you?; What would not be useful?; What should it include?; and, Would you buy it?

This brings us to the first of many reminders. Speak with your potential customers and users throughout the innovation development cycle (in research this is often referred to as the knowledge user or stakeholder). In fact, consider bringing knowledge users' and stakeholders' expertise onto your team early, often, and collaboratively (see Chap. 5, 47). Knowledge users and stakeholders can include patients, clinicians, decision-makers, or members of the public, and their presence on your team benefits your research when you invite them to be a partner or team member, not just a subject or participant (Canadian Institutes of Health Research, 2018; Holmes, Bryan, Ho, & McGavin, 2018; Kothari, Bickford, Edwards, Dobbins, & Meyer, 2011).

Note that it's sometimes challenging to identify who your customers are when working in health care and in technologies for supporting aging well. Your customer(s) could be patients, older adults, family or friend caregivers, housing providers, health-care providers, and decision-makers such as health authority leadership, health ministers, etc. It's important to consider as well that the user, payer (purchaser), and beneficiary of your innovation could be different people. For example, with a new health technology, the user could be the health-care provider, the payer could be the health authority, and the beneficiary could be the patient.

Now, pull these different pieces of information together to create a *value proposition*; this acts as a snapshot of what your product is, the problem it is solving, how it is different from other products, and who needs it (Emerson, 2003; Teece, 2010). A good value proposition highlights the strengths of the product, but does not overstate them. The proposition should be both intelligent and accessible. It conveys information succinctly and is crafted for the target audience (see Box 42.1). A value proposition, like a good research question, can help keep you focused and on task.

Box 42.1 Example Value Propositions
Assistive technology
"For powered wheelchair and scooter users, the backup camera system from CoPILOT solves the rearview visibility problem of powered mobility aides. Our system includes the camera, attachments, and armrest mount for your smartphone or tablet. Easy to install, charges when you plug in the chair, no extra steps" (source: Lupin Battersby).

An example of a value proposition used for marketing by Fundly: "Raise money for anything. Fundly is fast, easy, and has no raise requirements or start up fees" (https://fundly.com/).

Understanding What You Have

To understand what you have, you need to be familiar with some of the innovation terminology used in commercialization. First, innovations can include improvements to:

- A product (e.g., new type of hip protector).
- A process (e.g., more efficient process for blood management).
- A business model (e.g., Uber reimagined the taxi service business model).

Further, in each of those types of innovations, the innovation can be described as *radical*, which refers to something that makes significant improvements to a product, process, or business model that already exists or is something completely new. *Incremental innovations* refer to a stepped or moderate improvement to a process, product, or business model that is already available. *Generic innovations* are innovations that are so broad; they could have multiple different applications in different sectors (Maine et al., 2012). If you have a radical innovation, it's probably time to think about patenting; if it is generic, you might need multiple patents to cover all the potential applications. Alternatively, a land grab approach might involve simply capturing a large market share quickly through strategic partnerships (especially if the competitive edge of the innovation is primarily cost or first-to-market advantage rather than any significant IP).

Most academic institutions have an innovation office that can guide you through the patenting process. It is important to have legal advice regarding your rights and ownership as the institution might secure a significant part of the patents ownership in return for their aid. This is not an inherently negative consequence depending on your goals. We will explore this matter further.

Patenting *before* publishing is suggested. However, it should be noted that inventors have up to a year from public disclosure to patent in North America (for a discussion of the similarities and differences between Canada and United States in patenting, see http://www.smart-biggar.ca/en/articles_detail.cfm?news_id=625). Across most jurisdictions to be granted a patent you need to demonstrate that the innovation is new, useful, and not obvious (for more information, see https://www.wipo.int/patents/en/faq_patents.html#protection). Keep in mind that if you publish about your innovation, it will, as a consequence, no longer be new. Not all innovations are necessarily patentable. However, there are other instruments at your disposal to protect your intellectual property such as copyright, trademarks, and trade secrets. If you are not sure where your innovation fits, hire an intellectual property consultant. Check with your innovation office or ask colleagues for recommendations (for more on patents in academia, see Mowery & Ziedonis, 2007).

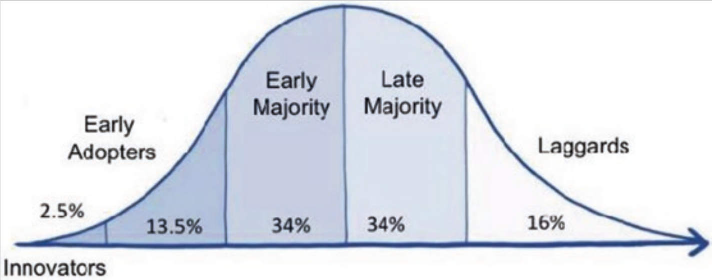
Ultimately, the value of the IP is largely determined by what the problems or challenges your innovation can solve and how it solves them. Being fully aware of this will facilitate your conversations about it in tangible terms. For a more thorough examination of this area, see Chap. 45.

Getting Your Innovation to Who Needs It

Before mobilizing your innovation, take stock of what is needed to make, market, and distribute your innovation, to get started map out your *value chain*. You must clarify where in the value chain your innovation is situated and how your innovation contributes to the final product. Your understanding of the practical use of the product by a consumer will help crystallize the contribution you are making. The value chain will also help determine who to explore partnering with, the resources needed, and how the product will reach target users (Maine et al., 2012). Looking at the value chain can also help you with determining how involved you want to be in launching or licensing the product.

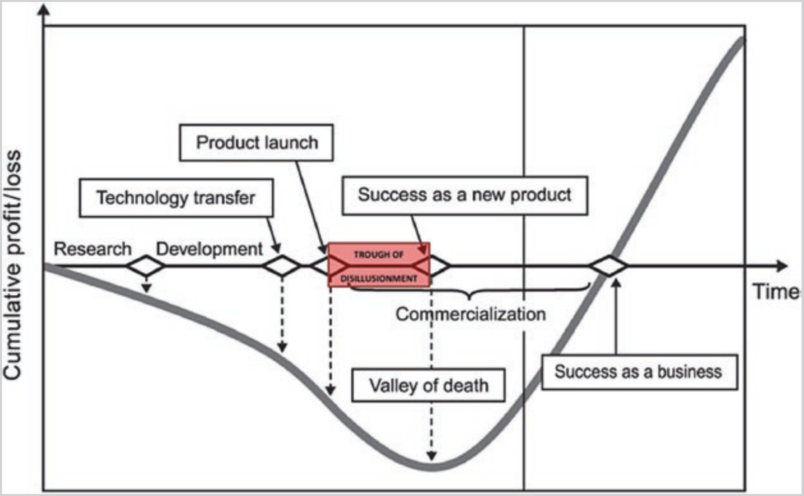
Unlike in the movie *Field of Dreams*, the advice—"If you make it they will come"—does not work for the adoption and diffusion of innovations. This is true whether you have a great published journal article, a new fun product, or a radical innovation. The value chain and value propositions, along with your knowledge user team members, can contribute to *adoption* and *diffusion* of your innovation (Dearing et al., 2017; Rogers, 2003). Many refer to the adoption curve (see Box 42.2) and the valley of death (see Box 42.3) when exploring the challenges in this area (Castro, Cox, & Fukumoto, 2017; Osawa & Miyazaki, 2006; Petersen, 2012; Rogers, 2003). The basic idea is that you need to market in a manner that aligns with your innovation and reaches the right audience (e.g., champions, early adopters, and policymakers), at the right time (e.g., policy window), to launch it successfully and make it over those valleys.

Box 42.2 Rogers Adoption/Innovation Curve



Note. Source: Castro et al. (2017), based on Rogers (2003, p. 247)

Box 42.3 Valley of Death



Note. John Petersen (2012) blog post, adapted from Osawa and Miyazaki (2006)

Finding Money

Whether you decide to license or launch, funding will be needed. There are a number of *non-dilutive* funding sources available to support research innovations and commercialization. Non-dilutive funding is money that you do not need to pay back or provide a financial return on investment (that would be *dilutive* funding).

Non-dilutive funding should be familiar to you; it includes research grants (e.g., Tri-Council Agencies funding), awards (competitions and prize money; your local business school would have information), and government programs (e.g., the National Research Council Industrial Research Assistance Program [NRC-IRAP]).

Then there are tax breaks (e.g., Scientific Research and Experimental Development Tax Incentive Program), competitions, and accelerator programs. Finally, there are investors: founder, family, friends, angel, venture capital, or alternative options such as crowdfunding or small investor connection programs such as FrontFundr.

Be sure to explore the non-dilutive funding options thoroughly. With the emphasis on impact of research, there are a number of new and ever-changing funding competitions from the Tri-Council (and beyond) such as Canadian Institutes of Health Research Rewarding Success competition or the Michael Smith Foundation for Health Research (British Columbia) that has the Innovation to Commercialization program (MSFHR Innovation to Commercialization (I2C) Program).

The how, when, and why of moving into dilutive funding are beyond the scope of this chapter. It is valuable for you to learn more if you are considering the entrepreneurial path of launching your research innovation. In the finding support section of this chapter, there are some suggested options for further learning.

Pulling It All Together into a Business Model

Whether you are going to launch or license, consider assembling your ideas, concepts, and consultations into a business model using the business model canvas. A *business model* has been defined by many, here is a succinct description: "Whenever a business enterprise is established, it either explicitly or implicitly employs a particular business model that describes the design or architecture of the value creation, delivery, and capture mechanisms it employs" (Teece, 2010, p. 172). Or, in lay terms, it is the summary of what you have, who wants it, how you can make it happen, why people will buy it, whether it will make any money, and how the money will be distributed.

The *business model canvas* (Osterwalder & Pigneur, 2010) is a tool for building, revising, and testing (iterating) your business model. It includes the following components: value proposition, customer segments, channels, customer relationships, key activities, resources, key partnerships, cost structure, and revenue streams. If that is a little more complex than what meets your needs, try the lean canvas, which is an adaptation of the business model canvas intended to be a fast tool for business brainstorming, developed to support the lean start-up movement (for more information see https://medium.com/@steve_mullen/an-introduction-to-lean-canvas-5c17c469d3e0). There are a number of business model canvas tools online, free and paid, and digital or print. You can use a whiteboard, a chalkboard, or even a napkin. Find something you like and make it work for you. There is a wealth of resources available explaining each of the canvas components too (e.g., Canvanizer). The key is to be creative, open, and curious. In summary, Table 42.1 outlines the key activities for commercializing research innovations within the Production Innovation Pathway model

Table 42.1 Product Innovation Pathway (PIP) model—commercializing research innovations

PIP level	PIP description	Key activities
1	Innovative ideas	Connect with your customers. Ask questions and explore whether this is useful to them. Is it better in an important way to what they already have? Explore the intellectual property value: Is it innovative? Can you patent it? Whose property is it? Do you need your institution involved?
2	Planning	Draft a business plan, ensure you consult early and often with experts, customers, and collaborators or partners. Be creative; allow yourself to explore possibilities. Revise your business plan, validate, revise, validate, etc. understand that it might change again in unanticipated ways
3	Development	Incorporate consultation feedback; change direction if needed (pivot); access non-dilutive funding; involve customers, and other stakeholders, in co-creation activities
4	Testing in real-world environment	Test often and early with prototypes, refine, revise, retest; consult with customers and experts; continue to identify market, value, and opportunities
5	Outcomes and impact	Track financials, successes, and failures, make your case, and look for investors or other funding opportunities. Fall in love with the problem, not your solution; this will open your eyes to opportunities and impact

The Product Innovation Pathway (PIP) model for Commercializing research innovations (Table 42.1) summarizes the ideas, tools, and pointers discussed in this Chapter.

Finding Support

Most academic institutions have an innovation office. This can be a great resource for you, particularly if you are interested in patenting and licensing your research innovation. The innovation office will help you determine other policies and practices related to intellectual property rights and ownership of research innovations.

For building your skills and your capacity, consider exploring opportunities for learning. For example, some universities have graduate certificates for just this scenario (e.g., Simon Fraser University's Beedie School of Business Invention to Innovation graduate certificate program or the University of Alberta's School of Business certificate in Innovation and Entrepreneurship). There are accelerators, incubators, and innovation hubs across the country that can provide learning and other supports such as MaRS Discovery District (Ontario), Innovation Boulevard and Innovate BC (British Columbia), Startup Zone (Prince Edward Island), TEC Edmonton (Alberta), and many more.

Another area to explore is social innovation; this area includes nonprofits and mixed business models; many of the concepts explored in this chapter apply here too, but with the additional objective and tasks of striving to have a socially minded impact. There are programs and learning opportunities such as Spring Activator, RADIUS, or the Centre for Social Innovation, to name a few.

Table 42.2 Commercialization resources and examples

Companies/programs	Websites
Alberta School of Business, Innovation and Entrepreneurship	https://www.ualberta.ca/business/programs/mba/degree-programs/innovation-entrepreneurship
Augerex	http://augurex.com/
Innovate BC	https://bcic.ca/
Beedie School of Business, Transforming Innovation to Invention	https://beedie.sfu.ca/commercialization-certificate/
Braze™ Mobility	https://brazemobility.com/
Canvanizer	https://canvanizer.com/new/business-model-canvas
Centre for Social Innovation	https://socialinnovation.org/
Coast Capital Venture Prize	http://www.sfu.ca/io/venture/venture-connection/VenturePrize.html
FrontFundr	https://www.frontfundr.com/en/
Fundly	https://fundly.com/
Hacking Health	https://hacking-health.org/
Innovation Boulevard	https://www.innovationboulevard.ca/
MaRS Discovery District	https://www.marsdd.com/
Manitoba Technology Accelerator	http://www.mbtechaccelerator.com/
MetaOptima	https://www.metaoptima.com/
National Research Council—Industrial Research Assistance Program	https://www.nrc-cnrc.gc.ca/eng/irap/index.html
RADIUS	https://radiussfu.com/
Spring	http://spring.is/
Startup Zone	https://startupzone.ca/
TEC Edmonton	https://www.tecedmonton.com/

Given the speed at which things change, these programs and options may be replaced with new ones. Thus it is important to reach out to colleagues and to be aware of your institution's resources as they can often point you in the right direction. Just be aware that there are resources and options available and explore them!

For reference, here is a listing of companies and programs mentioned throughout the chapter with their Web addresses (Table 42.2).

Key Messages

There are many pathways to creating impact with a research innovation. Do your homework, and learn more about the potential of commercializing your innovation, then:

- Put together a great, transdisciplinary team to help determine what you have and who needs it, and fill any gaps in skills that you need to grow the business.
- Identify the impact goal you have for the innovation as it will help you with key decisions along the way (e.g., scientific contributions, improving the health of Canadians, financial benefit, etc.).
- Access and leverage all of the opportunities for funding, learning, and accelerating a business; research what your institution and community offers.

- Draft a business model based on what you have learned, your goals, and your research.
- Next validate, edit, and reassess.
- Then leap.

References

Canadian Institutes of Health Research. (2018). *Patient engagement*. http://www.cihr-irsc.gc.ca/e/45851.html.

Castro, L. F., Cox, L. J., & Fukumoto, G. (2017). Diffusion of an agricultural innovation: A case study involving dry litter technology in American Samoa. *Technology in American Samoa, 1*, 1–12. https://www.researchgate.net/publication/317061409_Diffusion_of_an_Agricultural_Innovation_A_Case_Study_Involving_Dry_Litter_Technology_in_American_Samoa.

Dearing, J. W., Beacom, A. M., Chamberlain, S. A., Meng, J., Berta, W. B., Keefe, J. M., … Estabrooks, C. A. (2017). Pathways for best practice diffusion: The structure of informal relationships in Canada's long-term care sector. *Implementation Science, 12*(1), 1–13. https://doi.org/10.1186/s13012-017-0542-7

Emerson, J. (2003). The blended value proposition: Integrating social and financial returns. *California Management Review, 45*(4), 35–51. https://doi.org/10.2307/41166187

Holmes, B. J., Bryan, S., Ho, K., & McGavin, C. (2018). Engaging patients as partners in health research: Lessons from BC, Canada. *Healthcare Management Forum, 31*(2), 41–44. https://doi.org/10.1177/0840470417741712

Kothari, A. R., Bickford, J. J., Edwards, N., Dobbins, M. J., & Meyer, M. (2011). Uncovering tacit knowledge: A pilot study to broaden the concept of knowledge in knowledge translation. *BMC Health Services Research, 11*, 198. https://doi.org/10.1186/1472-6963-11-198

Maine, E., & Garnsey, E. (2004). Challenges Facing New Firms Commercialising Nanomaterials (July 1, 2004). Centre for Technology Management (CTM) Working Paper, No. 2004/02.

Maine, E., Lubik, S., & Garnsey, E. (2012). Process-based vs. product-based innovation: Value creation by nanotech ventures. *Technovation, 32*(3–4), 179–192. https://doi.org/10.1016/j.technovation.2011.10.003

Mehta, S. (2004). The emerging role of academia in commercializing innovation. *Nature Biotechnology, 22*(1), 21–24. https://doi.org/10.1038/nbt0104-21

Mowery, D. C., & Ziedonis, A. A. (2007). Academic patents and materials transfer agreements: Substitutes or complements? *Journal of Technology Transfer, 32*(3), 157–172. https://doi.org/10.1007/s10961-006-9011-1

Osawa, Y., & Miyazaki, K. (2006). An empirical analysis of the valley of death: Large-scale project performance in a Japanese diversified company. *Asian Journal of Technology Innovation, 14*(2), 93–116. https://doi.org/10.1080/19761597.2006.9668620

Osterwalder, A., & Pigneur, Y. (2010). *Business model generation: A handbook for visionaries, game changers, and challengers*. Hoboken: John Wiley & Sons.

Petersen, J. (2012, July 18). EVs, batteries and tales from the valley of death, [Blog post]. https://seekingalpha.com/article/728411-evs-batteries-and-tales-from-the-valley-of-death.

Rogers, E. M. (2003). *The diffusion of innovations* (5th ed.). New York: Free Press.

Teece, D. J. (2010). Business models, business strategy and innovation. *Long Range Planning, 43*(2–3), 172–194. https://doi.org/10.1016/J.LRP.2009.07.003

Chapter 43
Case Study 1: Blind Spot Sensors for Wheelchairs—Increasing Access to Independent Mobility

Pooja Viswanathan

The Challenge

Approximately 50% of older adults in institutions in Canada use a wheelchair for mobility. However, of those, only up to 50% can self-mobilize (Wang, Mihailidis, Dutta, & Fernie, 2011). Powered mobility allows individuals who cannot self-propel their wheelchair to gain independent mobility and, in turn, leads to an increased quality of life (Bourret, Bernick, Cott, & Kontos, 2002). Despite these benefits, however, powered mobility is often restricted in institutional settings due to safety concerns including injuring other residents (Wang et al., 2011). According to Arthanat, Nochajski, Lenker, Bauer, and Wu (2009), 52.8% of wheelchair users surveyed had experienced at least one accident that resulted in injury. Collisions are thus common among powered mobility device users, especially older adults, and the lack of environmental awareness can prevent safe operation of a powered wheelchair (Brienza & Angelo, 1996).

The objective was to find a solution that would allow independent mobility while ensuring safety, and none were commercially available.

Technology Push vs. Market Pull

A decade of research has been conducted at the University of Toronto, University of British Columbia, and Toronto Rehabilitation Institute through an emerging team grant, CanWheel, from the Canadian Institutes of Health Research (CIHR) and the

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AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence) (Viswanathan, Wang, & Mihailidis, 2013). However, the pathway to market was still not clear.

It became evident that market validation was a necessary step for successful commercialization of the research. There were several unaddressed questions, including those raised in discussions with a leading wheelchair controller manufacturer who had collaborated with Dr. Viswanathan as an industry partner through a Collaborative Health Research Project grant and as a participant in a workshop described in Viswanathan et al. (2018):

1. What would the value proposition be and for whom?
2. What would the main functions of the technology be?
3. What would the market segments be (including early adopters) and how big was the market?
4. What would the cost of the technology be?
5. Who would fund the technology?

Licensing the technology to an existing manufacturer would not be a viable option until these questions were answered.

Academic vs. Commercial Activities

The first step was to disclose all existing and relevant academic intellectual property (IP) to the research institution's innovation office. Discussions ensued regarding the commercialization potential of the existing IP. In the meanwhile, Dr. Viswanathan saw the creation of a start-up company as a potential way to get market validation and to find answers to some of the aforementioned questions in a systematic manner.

After incorporating a company in 2016, Braze Mobility Inc. (www.brazemobility.com), and enrolling in the Impact Centre's (AGE-WELL core facility) Techno program, Dr. Viswanathan started to fill out a *business model canvas*. The IP created by the start-up was clearly delineated from academic intellectual property. This was done by maintaining different work spaces and notebooks, for example. The IP initially consisted simply of interviews (know how) with various potential stakeholders. Dr. Viswanathan engaged with an AGE-WELL community partner, March of Dimes, and organized workshops through their Learning Information for Future Empowerment (LIFE) program. She also hosted an *Ideathon* to encourage a more diverse audience to have conversations about mobility and current barriers. She engaged often with clinicians at the Assistive Technology Clinic, a leading seating clinic in Ontario, receiving feedback on various aspects such as ease of installation, cost, funding, users who could benefit, etc.

The Start-Up "Pivot"

Problem interviews with potential customers highlighted that rear visibility (or lack thereof) when driving is a significant problem that often leads to collisions. Unlike the previous research, which focused on semiautonomous control of wheelchairs (e.g., automatic collision avoidance), a new add-on technology was invented by Braze Mobility that mounts on any wheelchair and provides multimodal alerts to the driver regarding objects in blind spots. While the academic team had mostly consisted of software developers, at Braze Mobility, Dr. Viswanathan hired industrial design as well as mechanical and electronical engineering interns to fill the gaps in hardware expertise and design for manufacturing. Once a proof of concept of blind spot sensors was validated with potential customers (through solution interviews), as well as with attendees of various local conferences, prototypes were iteratively built and validated through a beta client program. In the program clients received trials of the prototype in exchange for a safety deposit of a few hundred dollars. This *ownership* of the product incentivized beta clients to give the team timely and regular feedback on the product. This feedback inspired more accessible designs that would enable product use by a larger population. Various factors were rated by clients (aesthetics, cost, adaptability, ease of installation, etc.), and the most important features (to the wheelchair users) were prioritized. In the case of installation, close attention was also paid to therapists, family members, and wheelchair distributors, who would likely be involved in installation. The team also sought advice from the Semaphore Lab at the University of Toronto (AGE-WELL core facility) regarding how to design with larger-scale manufacturing in mind (i.e., 3D printing design principles, designing for injection moldings, etc.). This allowed the team to move from prototypes to market-ready products in a cost-effective manner (Fig. 43.1).

The Launch

Once traction was seen among several wheelchair users and key opinion leaders (therapist and established manufacturers and/or distributors), experienced industrial designers were sought as consultants in order to complete design for manufacturing.

Fig. 43.1 Braze sentina prototypes
Photo Credit: Catherine Lu

Manufacturing partnerships in China and local contractors for sourcing and production of electronics were finalized. A soft launch was conducted by Braze Mobility at the AGE-WELL Annual General Meeting in Winnipeg in 17 October 2017 (https://www.newswire.ca/news-releases/braze-mobility-unveils-obstacle-detection-system-for-wheelchairs-651453403.html), only a year and a half after incorporation. More recently, in January 2019, Braze launched online sales of its products directly to consumers in North America: www.brazemobility.com.

Outcomes and Impact

A major outcome was a commercial blind spot sensor system for wheelchairs. The first run of soft launched units was sold out within 6 months to wheelchair users, rehabilitation hospitals, long-term care facilities, and distributors in the United States and New Zealand. In February 2018, a resident who uses a powered wheelchair at a long-term care facility in Ontario, was identified as being at high risk of collisions. Staff sought a solution that would enable the resident to maintain his independence while minimizing safety risks. After finding the Braze products through word of mouth and online searches, the staff purchased a training kit from Braze and trialed the system with the resident for a few months. Pleased with his improved driving performance with the Braze system, the therapist put in an application for funding. The resident's system was fully funded, enabling him to maintain his independence and mobility with a system he is proud to call his own.

One of the pitfalls of research is that the value of informal, unstructured interactions with end users is often undermined. Approval from a research ethics board can take a long time and is required in order to publish data. However, early informal interactions with users can provide valuable insights regarding the market *readiness* and acceptance of a technology. The business model canvas (or lean canvas) should be explored as a first step in research projects while keeping in mind that it is not a static document. As one continues to learn about the size of the potential market, the competitive landscape (or other alternatives available to the user), and pain points and needs of the user, there might be several *pivots* that become necessary, not only with respect to the technology itself but also the target market and mechanism of delivery (sales/marketing channels, cost, etc.). Engaging in this dynamic and interactive process right from the start can accelerate the rate at which research innovations are commercialized (successfully).

Key Messages

- Engaging with users is critical, and community partners play a key role in connecting innovators with those who can benefit from their inventions.
- When users feel like owners of the technology and that they have more "skin in the game," they feel empowered and inspired to co-create solutions that will solve their problems—and nobody knows their problems better than they do.

- Get the products into customers' hands as early as possible. Improvements will keep happening. It's better to get a product in people's hands that is *good enough* (i.e., solves a specific problem reasonably well), rather than continuing to work toward a *perfect* product that tries to do too many things and never exits the research lab.

Project Details and Team Current team members include Dr. Pooja Viswanathan (Co-founder and CEO), Dr. Alex Mihailidis (Co-founder and Scientific Advisor), Terrence Ho (Head of Customer Success), David Beckett (Product Lead), and several contractors and customer development partners who are wheelchair users themselves.

References

Arthanat, S., Nochajski, S. M., Lenker, J. A., Bauer, S. M., & Wu, Y. W. (2009). Measuring usability of assistive technology from a multicontextual perspective: The case of power wheelchairs. *American Journal of Occupational Therapy, 63*(6), 751–764.

Bourret, E. M., Bernick, L. G., Cott, C. A., & Kontos, P. C. (2002). The meaning of mobility for residents and staff in long-term care facilities. *Journal of Advanced Nursing, 37*(4), 338–345. https://doi.org/10.1046/j.1365-2648.2002.02104.x

Brienza, D. M., & Angelo, J. (1996). A force feedback joystick and control algorithm for wheelchair obstacle avoidance. *Disability and Rehabilitation, 18*(3), 123–129.

Viswanathan, P., Wang, R. H., & Mihailidis, A. (2013). Wizard-of-Oz and mixed-methods studies to inform intelligent wheelchair design for older adults with dementia. In *12th European AAATE conference*, 19–22 September, 2013, Vilamoura, Portugal.

Viswanathan, P., Wang, R. H., Sutcliffe, A., Kenyon, L., Foley, G., Miller, W. C., Bell, J., … Carlson, T. (2018). Smart wheelchairs in assessment and training (SWAT): state of the field, AGE-WELL Report. https://agewell-nce.ca/wp-content/uploads/2019/01/SWAT-State-of-the-field_FINAL.pdf.

Wang, R. H., Mihailidis, A., Dutta, T., & Fernie, G. R. (2011). Usability testing of multimodal feedback interface and simulated collision-avoidance power wheelchair for long-term-care home residents with cognitive impairments. *Journal of Rehabilitation Research & Development, 48*(7), 801–822.

Chapter 44
Case Study 2: The Java Project—The Evolution of Peer Support and Mentoring in Residential Care

Kristine Theurer

The Challenge

Loneliness and depression are significant global health-care challenges in the twenty-first century affecting as many as one out of two older adults living in residential senior care. Despite recreation calendars filled with programs and events, residents describe in their lives a lack of meaning and purpose (Knight & Mellor, 2007), chronic loneliness (Drageset, Kirkevold, & Espehaug, 2011), and depression (Canadian Institute for Health Information, 2010). The endless diet of entertainment and distraction leaves residents hungry for meaningful connections and purpose (Theurer et al., 2015). Psychosocial care for residents is based on the presumption of absent abilities and that their problems can only be fixed by a professional. Residents, however, are very capable of supporting each other (Theurer, Wister, Sixsmith, Chaudhury, & Lovegreen, 2014), and this approach positions them as engaged citizens who have social agency. The Java Project looked at how residents could become active contributing social citizens in improving the quality of life for themselves and their peers through structured peer support and mentoring.

Initial Development

Dr. Kristine Theurer developed and piloted two peer support groups for this population called the Java Music Club and Java Memory Care (for people living with dementia) and a peer mentoring program called Java Mentorship. The pilots included residents and staff in a way that not only facilitated their input but also

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implemented their ideas and testing and retesting them using an iterative process. While it took more time, we used a mixed methods process evaluation in order to shape these programs before evaluating outcomes. The benefit of fully engaging staff and residents meant that the programs worked in real-life situations. Two of the biggest barriers we encountered along the way were lack of time for staff and their need for additional education to sustain the programs. Therefore, we focused on making the programs easier to deliver and developed clear step-by-step guides, facilitator training videos, and webinars.

Development of the Business and Commercialization

In keeping with the knowledge translation efforts to incorporate evidence-based research into the practices of health professionals, a company called Java Group Programs (Java) was formed in 2011 in order to disseminate the programs into policy, programs, and practice: www.JavaGP.com. One key lesson we learned about knowledge mobilization was that it isn't enough to have a great innovation, publish articles, and present at research conferences—it took a long-term commitment, a team, and a grand collaborative spirit. For us this meant a substantial investment of financial and time resources in order to present regularly at industry conferences; offering trainings and webinars for practitioners, stakeholders, and institutions, maintenance of a website and social media; and developing partnerships with like-minded organizations. Examples of partnerships included pilots with the Schlegel-UW (University of Waterloo) Research Institute for Aging, presenting national webinars with the Alzheimer Society of Canada, and becoming a value-added partner with the Eden Alternative in the United States. Java also participated in collaborative research, such as a knowledge mobilization project with the Ontario Centres for Learning, Research and Innovation in Long-term Care (CLRI), Carleton University, and Bruyère Continuing Care (funded by the Centre for Aging and Brain Health Innovation (CABHI), Carleton University, and the Government of Ontario) to implement Java in rural Ontario.

Toward a Digital Platform

In order to increase scalability of the Java programs, the next step was to explore a digital prototype, starting with the Java Music Club. To develop the prototype, we worked with Emmetros, an Ontario software product development company, who observed Java Music Club meetings and conducted interviews with 12 facilitators at 8 residences. After development of the digital prototype, they conducted user feedback sessions with six Java facilitators. Findings suggested a definite preference for the digital prototype over a paper-based approach, that it met user expectations and that the user interface and navigation system was intuitive and easy to use.

Facilitators noted some barriers and suggested added features including the ability to add and/or delete group members, add notes for participants, and access new themes and training and system integration. We are currently exploring next steps to add these revisions and build out the digital platform through incorporating revenue, investment income, and grants.

The most recent research on the Java programs demonstrated a significant reduction in loneliness and depression scores over a 6-month period among residents conducting peer mentoring *and* among residents being supported by their peers, and there was a 60% increase in program attendance (Theurer et al. 2020a, b). In their interviews, staff reported a reduction in stress levels and burden. Residents described experiencing multiple benefits from helping their peers—that through helping others, they were also helping themselves. As one mentor stated: “It takes the loneliness away.” As a result of teamwork, numerous collaborations, and partnerships, Java programs are now in over 1000 organizations across Canada and the United States. Customers include three of the largest senior living organizations, Chartwell (Canada), Revera (Canada), and Brookdale (United States). Probably our single most important learning is captured in an oft quoted proverb: “If you want to go fast, go alone. If you want to go far, go together.”

Key Messages

- The success of the Java project demonstrates that despite challenges, empowering residents to help to reduce loneliness and depression within residential senior care represents an optimal approach to building better mental health.
- Collaboration, partnerships, and time are essential for researchers to translate innovative ideas into real-world services and impact.

Project Details and Team The research for the Java Music Club ran from September 2006 to May 2010, and the team consisted of Kristine A. Theurer, Andrew Wister, Andrew Sixsmith, Habib Chaudhury, and Loren Lovegreen from the Simon Fraser University. For Java Mentorship, the research ran from September 2013 to December 2018. The team consisted of Kristine A. Theurer, W. Ben Mortenson, Melinda J. Suto from the University of British Columbia; Robyn I. Stone, LeadingAge LTSS Center @UMass Boston; Virpi Timonen, School of Social Work and Social Policy of Trinity College Dublin; and Susan Brown of the Schlegel–UW Research Institute for Aging. The work was supported in part by the Social Sciences and Humanities Research Council of Canada [766-2007-0656] and [767-2014-2411], and the Michael Smith Foundation for Health Research [ST-JGS-01379-(07-1)POP] awarded to Kristine Theurer. Initial partnerships included the Schlegel–UW Research Institute for Aging, Schlegel Villages, Ontario Association of Residents’ Councils (OARC), and the residents, staff, and volunteers of care homes in British Columbia and Ontario.

Declaration of Conflicting Interests Dr. Kristine Theurer presents Java programs at conferences and to health professionals and receives financial remuneration for workshops and program materials.

References

Canadian Institute for Health Information. (2010). *Depression among seniors in residential care*. https://secure.cihi.ca/free_products/ccrs_depression_among_seniors_e.pdf.

Drageset, J., Kirkevold, M., & Espehaug, B. (2011). Loneliness and social support among nursing home residents without cognitive impairment: A questionnaire survey. *International Journal of Nursing Studies, 48*(5), 611–619. https://doi.org/10.1016/j.ijnurstu.2010.09.008

Knight, T., & Mellor, D. (2007). Social inclusion of older adults in care: Is it just a question of providing activities? *International Journal of Qualitative Studies in Health and Well-being, 2*(2), 76–85. https://doi.org/10.1080/17482620701320802

Theurer, K., Wister, A., Sixsmith, A., Chaudhury, H., & Lovegreen, L. (2014). The development and evaluation of mutual support groups in long-term care homes. *Journal of Applied Gerontology, 33*(4), 387–415. https://doi.org/10.1177/0733464812446866

Theurer, K., Mortenson, W. B., Stone, R., Suto, M., Timonen, V., & Rozanova, J. (2015). The need for a social revolution in residential care. *Journal of Aging Studies, 35*, 201–210. https://doi.org/10.1016/j.jaging.2015.08.011

Theurer, K. A., Stone, R. I., Suto, M. J., Timonen, V., Brown, S. G., & Mortenson, W. B. (2020a). Reducing loneliness and depression: The power of peer mentoring in long-term care. *Journal of the American Medical Directors Association, 21*(1), 137–139. https://doi.org/10.1016/j.jamda.2019.08.011

Theurer, K. A., Stone, R. I., Suto, M. J., Timonen, V., Brown, S. G., & Mortenson, W. B. (2020b). The impact of peer mentoring on loneliness, depression and social engagement in long-term care. *Journal of Applied Gerontology*. https://doi.org/10.1177/0733464820910939

Chapter 45
Dealing with Intellectual Property at the Early Stages

Richard McAloney, Emanuel Istrate, and Jeffrey Buchholz

The Challenge

Intellectual property (IP) refers to creations of the mind. These intangible assets are a valuable part of any business, whether it provides products or services. From a legal perspective, IP rights provide the creator the right to control the results of their work and derive benefits from them. For a comprehensive IP strategy, you must consider, for example, the industry sector, overall business strategy (startup, licensing, etc.), resources available, competition, and how fast the industry is changing. This chapter will discuss the challenge of dealing with your IP at the early stage, to enable the successful commercialization of your research and technology.

Innovation in health care and health service delivery can make a huge difference in peoples' lives. To achieve this you must turn your research into a product and find a way to bring it to market. What good is research if doesn't make it to the intended beneficiary, particularly in areas such as health and technology? The problem is that your main focus is to perform world-class research and ultimately bring this knowledge to the world through publications and presentations.

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It has become increasingly common in the last decade for researchers to think about commercialization. At times, funding applications require some attention as to how you would bring the idea to market. Gone are the days when commercialization was a *dirty* word in the halls of academia, and it is now a ubiquitous part of the overall conversation about research. This is a positive trend as it ultimately improves the output of university research and brings more products and services to the world.

Key Ideas

Know the IP Policy of Your Institution

When you start to develop your idea into a prototype, this is the time to begin thinking about IP. Did you know that your institution has an *inventions policy*, and if so, what is that policy? Research institutions typically have an office that manages the IP portfolio and commercialization activities, classically referred to as the *technology transfer* office (Innovations & Partnerships Office, 2018). Sometimes this can be an external body, such as is the case with the University of Alberta's partnership with TEC Edmonton. As a first step, get to know the professionals at your institution who manage commercialization and can support these activities. The IP policy of your institution can be found online (Innovations & Partnerships Office, 2018). The policies at institutions across Canada range from the IP being solely owned by the inventors (*inventor owned*) or wholly owned by the institution (*institution owned*). There is a wide range in between where ownership is shared (*joint ownership*). Often, the inventor also has the choice to take the lead in commercialization or to turn it over to the university (*inventor choice*).

Box 45.1 illustrates the process of working with your institution in the case of a joint ownership policy wherein the inventor could elect to turn over the invention to the university. The university assesses the market potential and chooses whether or not to invest resources (such as patenting costs). You will no doubt be involved in some capacity. Given the resources invested, the university will hold a larger equity share than in the case where the inventor provides all resources. Ensure that the roles and expectations are clearly defined.

Research can have multiple institutions involved in one project. Since IP policies across Canada vary, it is necessary to establish at the beginning of a project how IP will be handled. The project may have an industry partner, in which case you should check the research contract for any statement of IP ownership.

The process begins with filing an invention disclosure with the institution as a formal written notice of the invention. This confidential document tracks the nature of the invention, the inventors, contributors, and any partners involved in generating the invention. Universities will have an invention disclosure form to complete, and companies should have their own internal disclosure procedures.

Box 45.1 Example of Working with a University
A professor and Ph.D. student discovered a rubber material that doesn't slip on ice. They decided to create a company called SureSole. They filed an invention disclosure with the *technology transfer* office.

The IP policy is joint ownership with *inventor choice*. The inventors elect to take ownership of the IP. They worked with a patent agent to file a United States provisional patent for $3000. The university assigned the invention to the inventors under an assignment agreement so that the inventors now own the IP.

The institution's policy states that the university retains 25% of the net revenue (from sales or licensing) and the inventors retain 75%. SureSole will not generate revenue for some time as they develop their product and scale up manufacturing. It is extremely difficult to assess the value of the company at this stage and to define the compensation for the university. There are many variables to consider including market size, strength of IP, and if the IP is part of a larger portfolio. The institution likely wouldn't own 25% of SureSole in this case. The university agrees to 5% of the SureSole shares and now own equity in the company. There is no standard but typically in the range of 1–10%. The inventors have a lawyer, who specializes in intellectual property law and writes an assignment agreement, so SureSole owns the IP. They now start writing government grants and engaging investors. Researchers can now present at conferences and publish, as long as they file the full patent in 12 months.

Patents and the Patenting Process

You have a great idea and now all you need is a patent and you'll make a lot of money—right? The reality is that most patents don't create any value. It is easy to find examples of this in the patent literature, with patent number US3216423A being a favorite example. The title of the patent is: *Apparatus for facilitating the birth of a child by centrifugal force*. Yes, it is true! A patent was issued for a table that an expectant mother can lay upon that spins around to aid in the birthing process! No doubt this was a serious invention that might be useful, but given how we don't see such a device in the delivery room, it didn't create value for the inventor (or licensee, if that's the case). Given the limited resources at the early stages in the innovation pipeline, you must carefully strategize how to effectively protect inventions as you bring them to market.

Utility Patents

A patent can be obtained for a new and useful process, machine, manufacture or composition of matter, or any new and useful improvement thereof. A utility patent gives an inventor the right to exclude others from making, using, selling, and importing an invention. This is a time-limited monopoly of 20 years in most countries. You need a patent in each country where you do business and want to have protection. In exchange for the patent rights (this is the patent bargain), you are required to publicly disclose the invention. Patentability is judged on whether the invention is:

1. Novel: The invention must not be part of the state of the art. Essentially it can't be found or known publicly.
2. Nonobvious: It wouldn't be obvious for a person having ordinary skill in the art to take known elements and deduce the invention.
3. Useful: The invention must be capable of something *useful* providing some benefit.

Anything that exists in the public domain is referred to as *prior art*. To obtain a patent, there must be no prior art, or you must improve on existing prior art. Public disclosure of any sort constitutes prior art. The United States and Canada do give you a 1-year grace period after you have disclosed the invention publicly. This means that you can still apply for a patent for 1 year after you publicly disclosed. Relying on this 1-year grace period is strongly discouraged, because it wouldn't protect you outside of North America. A conference presentation, even at a small workshop, is considered public disclosure. Always file before presenting, publishing, or selling.

A patented invention could rely on many other patented subcomponents, and getting a patent doesn't automatically give you the right to ignore those other patents. For example, one could get a patent on a new type of pen. Inside the pen, however, someone else could have already patented the ink. Having the patent to the pen doesn't automatically give the right to use the ink. This is the question of *freedom to operate*.

Currently, in the United States, the threshold standard for software (in addition to novelty and nonobviousness) is that the software patent claims must encompass only an abstract idea. Although there are several tests, a claim that transforms some article, or is performed by a machine, will pass the abstract idea test and be patentable subject matter.

Patenting Timelines

It is common to start the protection process by filing a Provisional Application for Patent at the United States Patent and Trademark Office (USPTO). The provisional application is offered by the USPTO, and it allows someone to submit an application quicker and at a lower initial cost. The procedure is fairly simple, but it doesn't automatically result in a patent; in fact, an examiner won't even review it. Instead, it gives you the right to submit a full patent application within a year. If you submit the full application by that time, you can rely on the priority date of the provisional application. If you don't file a full application, then the provisional expires. Because provisional applications are not published, your invention would stay secret.

There are conflicting views on provisional patents. This may be the only option given funding and time constraints of the researcher or startup. The provisional patent sets the priority date giving you a year to work on your strategy and raise funds. In a perfect world with infinite resources, you would submit a full patent application from the beginning and gain protection in every country, but in the real world, provisional applications are useful vehicle to protect your IP.

You may have heard someone say, “I have an international patent.” There is no such thing as an all-encompassing international patent. However, in order to make it administratively a bit easier to apply for patents in multiple countries, the Patent Cooperation Treaty (a PCT patent) allows you to make a single application first and decide within 30 months of the priority date (the first application date) which countries you want to apply for a patent. PCT applications are filed within 12 months of the priority date set by a provisional patent application. At 18 months from the priority date, your application is made public. This is important because at this stage, everyone sees it, and in the event you don’t move forward, you lose all potential to protect the invention in the future.

As shown in figure 45.1, for the PCT route, national applications are filed 30 months from the priority date. By this time, you need to know in which countries you will file and have the funds for translation, legal fees, and filing fees in each country. Somewhere in the 30-month window, you should get a report back from the World Intellectual Patent Organization (WIPO). The examiner’s report will be key in helping you understand the likelihood of the patent issuing, how strong it is, and key variables in executing your strategy. Box 45.2 summarizes a typical PCT patent filing procedure (refer to the World Intellectual Property Organization website: https://www.wipo.int/portal/en/index.html).

Box 45.2 A Common Patent Filing Timeline

Returning to the theoretical example of SureSole from Box 45.1, this is how they proceeded with IP protection:

- SureSole decided to protect the formulation of its anti-slip rubber.
- The student needed to go to a conference, so they made a provisional patent application on 1 October 2014.
- In early 2015 they received government funding and confirmed from early prototypes that this was useful (this is reduction to practice or an embodiment of the invention).
- In September 2015 they proceeded with a PCT application, because they didn’t have the funds to do national application at the time.
- On 1 April 2016, their application was published on the WIPO website.
- Throughout 2015 and 2016, they refined their business model and raised some funds. They ended up deciding that they want to expand their business mainly in Canada, the United States, the European Union, and Japan based on manufacturing location and market size.
- In early 2017 they started working on filing national applications, which involved translations and collaborations with patent agents in those countries.

How much does it cost to get a patent? Here is a concrete answer: it depends. There are filing, drafting, legal, translation, and maintenance fees throughout the life of the patent. If you don't pay the maintenance fees, protection is lost. You'll have to strategically choose in which countries to file. People often add a country to the list if they consider that country *an important market* for them, if a competitor is very active there, if this industry typically manufactures there, etc.

For the most general of guidelines, budget about CDN $5000–10,000 for filing a provisional patent, if you use a patent agent. Some are brave and draft their own provisional and only pay hundreds but, not being a professional, there are obvious risks. You'll need more funds (another $5000–20,000) at the twelfth-month mark to file the PCT application and again 18 months later when you file in individual countries. The costs increase the more back-and-forth discussions with the patent office require your agent's time. It could easily be well over $100,000 over the life of the patent. Refer to Fig. 45.1 for a general overview of the timeline for the PCT route.

Design Patents

Design patents protect the shape, configuration, and ornamental features of a product. Think about the shape of the iPhone or the overall look and layout of a digital application. Although designs generally may have easy work arounds, a design which also captures functionality can be very valuable (e.g., the design of the swipe-to-open button or the shape of a device reliant on its geometry for its utility). Design patents, just like utility patents, must be registered in each country where you want to be protected and have a life of 10 years in Canada.

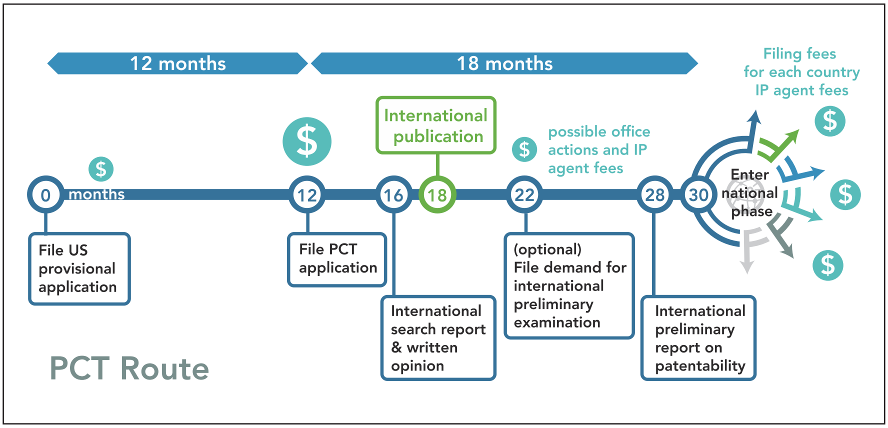

Fig. 45.1 PCT Route. *Note.* Graphic provided by Harim Ulfig, Impact Centre

Key Ideas

Patent Searching, Freedom to Operate, and Reading Patents

You'll need to decide what and how to patent and also if there are existing patents that you might need to license. This is what's called a *freedom to operate search*. It evaluates all non-expired patents, mapping how their claims align with aspects of your invention. It is quite likely that a search will find patents that overlap with what you want to do. Following the patent literature like you do papers, will give you a wider scope on the prior art and help you assess your freedom to operate. The most important part of the patent are the *claims*. The claims section of a patent contains a list of items over which the patent holder gets control.

Patent searching

The USPTO (https://www.uspto.gov) and the WIPO (https://www.wipo.int/portal/en/index.html) are good places to start searching. There are other search engines such as Google Patents (https://patents.google.com). Start by searching the names of people in your field or companies whose literature you already follow. Names can be in the inventor field or in the assignee field. You can search by keywords, but keep in mind that the patent literature may use different keywords than you are used to. Once you find a few patents, you can find other prior art using the patent classification number for a patent, which groups patents of similar subject material. You can also look at backward and forward citations. Keep detailed records of your search.

Types of Intellectual Property Other Than Patents

Research often leads to the development of IP. Trade secrets, design patents, trademarks, and copyright should be considered as part of an overall comprehensive IP strategy. Each type of IP has unique areas of applicability, costs, and benefits. Although the impression of some people is to rush out and patent any invention, the decision is far more complex. Decisions should combine technical and business strategy. Box 45.3 summarizes the various forms of IP that should be assessed (Gaff, 2017).

Dealing with Partners and Employees

Along the innovation pathway (see Table 45.1), you will have discussions with many stakeholders and partners. They may require that you disclose sensitive information. A confidentiality agreement or nondisclosure agreement (NDA) can help to protect the information. A mutual nondisclosure agreement (MNDA) is just a two-way version where both parties can share information and have it remain

Box 45.3 Other Types of IP to Consider

Type of IP	What is protected	Examples	Key relevance for health researcher
Copyright	Works of expression Protection from creation for the life of the author plus 50 years	Literary books Music Art Computer programs Instruction manuals Papers Website material Marketing material	Computer code and programs. Researchers should pay special attention when doing sponsored research that entails development of software and how it will be transferred or licensed. Get contract terms in place at the beginning of project. Most sponsors will prefer if you waive moral rights.[a]
Trademark	Words, logos, product name, company name, symbols, sounds, slogans, etc. associated with a business Protection in Canada is indefinite with a 15-year registration term as long as it's used	You're constantly bombarded with examples of trademarks from your favorite products, marketing materials, and logos. Just look around	Essentially protects your brand to ensure customers associate you with the trademark. Registration is not required but gives broader coverage. To register you must prove first use. Keep detailed records as it's guaranteed that when you get to file 5 years later, you won't be able to find the information! Keep copies of first flyers, screenshots of websites, use of company email addresses, etc.
Trade secret	Formulas, methods, devices, compilations of information (confidential and economic advantage) Protection is infinite or as long as it's secret	Datasets (e.g., for AI or machine learning researchers) Formulations (e.g., Coca-Cola) Production methods Market information and strategies Business information Survey methods	Benefit: No cost. Risk: Secret gets out. Is it easy to reproduce?

Note. [a]Copyright law in Canada protects moral rights (noneconomic rights): the right to attribution, integrity, and anonymity. An industry sponsor will not want to restrict their ability to commercialize and will likely want a researcher to waive moral rights. See Government of Canada webpage: https://www.canada.ca/en/heritage-information-network/services/intellectual-property-copyright/nailing-down-bits/moral-rights.html.

Web links from Canadian Intellectual Property Office (CIPO) for *A guide to copyright*. https://www.ic.gc.ca/eic/site/cipointernet-internetopic.nsf/eng/h_wr02281.html.

Trademark: https://www.canada.ca/en/services/business/ip/trademarks.html.

Government of Canada: *What is a trade secret?* https://www.ic.gc.ca/eic/site/cipointernet-internetopic.nsf/eng/wr03987.html.

Table 45.1 Product Innovation Pathway model (PIP)—intellectual property

PIP level	PIP description	Key activities
1	Concept (invention)	Write research grants and execute research projects Assess potential inventions (what would be patentable). Make this part of the discussion in regular meetings Understand the institution IP policy and file invention/copyright disclosures Protect IP before presenting or publishing
2	Planning	Build prototypes for user engagement Follow patent literature to determine patentability and freedom to operate Reassess potential inventions (what would be patentable) Draft patents and/or engage patent professionals Do market intelligence research Examine team deficiencies Do secondary market research
3	Development	Complete working prototype for testing phase Discuss business strategy (Licensing? Startup?) Do primary and secondary market research Determine your customer (Who will pay for your product? The user may be different from the customer) Assess team needs Consider all forms of IP
4	Testing	Test prototype in real setting File IP before extensive testing, trial, or pilot is conducted Get appropriate agreements in place for testing phase (pay attention to potential for IP creation and define ownership) Use feedback and results to refine product
5	Implementation	Define commercialization path Create company if appropriate Assign IP rights to desired entity Build team Raise funds to continue product development Establish manufacturing Do marketing and sales activities

confidential. You'll hear conflicting points of view on whether or not NDAs are worthwhile. The bottom line is it's better to have some level of protection for your confidential information. An Internet search will provide many examples of NDAs; be sure to read and select the most appropriate for your circumstances. Additionally, your university technology transfer office, the Canadian Bar Association (https://www.cba.org/Home), American Bar Association (https://www.americanbar.org/), and the Association of Corporate Counsel (https://www.acc.com/) may have resources available on their websites.

NDAs are not bullet proof, so err on the side of caution. You are always free to negotiate the contents of an NDA. Investors generally won't sign NDAs as they see many companies, and signing so many NDAs would make it impossible for them to communicate with people. The most important clauses to review are:

1. The obligation of confidentiality and to what standard. Generally, most NDAs require the recipient of confidential information to protect the information as strongly as they protect their own confidential information, or at least to a commercially reasonable degree.
2. Exceptions to confidential information, for example, information already publicly available and information developed by the recipient without using the discloser's information, among others.
3. Length of confidentiality obligation, which can, and often does, extend beyond the term of the agreement.
4. What to do with information in a recipient's possession when the agreement expires or is terminated. Usually the information is to be returned and/or destroyed.
5. What sort of information is covered? Does it have to be in writing or does oral disclosure count too?

Your team is probably the single most important contributor to success. All parties involved should assign their IP rights over to the entity responsible for commercialization, most typically the institution or startup. Get the IP assignment early as tracking them down years later can be challenging. It is common to have a shareholders agreement executed at the same time as the assignment agreement (Cattanach & Bellavia, 2017). The shareholders' agreement (SA) is a contract that defines the relationship between shareholders and lists the allowed activities (Cattanach, 2018). Generally, it defines issues like decision-making; what happens if a shareholder (SH) leaves (claw back); frequency of board meetings; drag along (if the majority of SH agree to sell, all must sell); tag along (if majority of SH receives an offer to buy their shares, minority of SH can sell at the same price); shareholdings; and period shares that are earned (vesting period), among others. Useful information can be found at the Canadian Bar Association, American Bar Association, Association of Corporate Counsel, and even local bar associations' websites.

Finding Support

- All research universities and hospitals have technology or licensing offices, and you may be obligated to work with these offices due to employment agreements and the nature of the work (e.g., sponsorship, grants, and other funding sources). Be sure to understand your employment agreement to know your obligations. They may be able to provide contacts and information to other resources appropriate to your particular circumstances.
- Entrepreneurship programs—most universities have at least one incubator or accelerator. The programs may have resources available to innovators and entrepreneurs, whether in the form of programs, mentorship, or even direct grants. Independent entrepreneurship or incubator programs, even without entering such a program on a contractual basis, can point you to programs or offerings that are better suited to your individual situation.

- When working with IP professionals, be sure to find one that knows the field you are in. You won't need an NDA with your lawyers and agents; this is the professional responsibility as part of their business. Read some of the patents they have written (patent agents are searchable by the lawyer or agent that filed them), and better yet, speak to others that have worked with them. Ideally, you should file the best application possible from the start. However, every case is different, so be sure to convey your business goals, potential for public disclosure, and what you can afford. If an agent or lawyer doesn't talk to you about your business goals, it's a red flag. Some professionals may offer to work for equity to draft your IP. Giving equity to anyone should not be taken lightly and is not advised when working with any service provider unless there is a long-standing trusted relationship and may be prohibited depending on the jurisdiction.

Key Messages

Commercialization of your research should not hinder your research. Properly protecting the intellectual property is a key first step. Starting off right will give the best chance of success. Table 45.1 provides a detailed look at the key activities along the PIP and use the short checklist below to get started:

- Look up your institutions' IP policy to determine ownership.
- Get to know your IP office.
- File invention disclosures.
- Search the patent literature to determine what is patentable and if you have the freedom to operate.
- Consider your overall commercialization strategy early, and revisit often as you gather market information.
- Protect the IP before publishing or public disclosure.
- Examine all other forms of potential IP.
- Negotiate contracts with partners at the *beginning* of a project.
- Execute NDA/MNDA's with external partners before engaging.
- Ensure the team understands what is expected of each shareholder.

The Government of Canada's *Intellectual property strategy* website has good general information: https://www.ic.gc.ca/eic/site/108.nsf/eng/home. Always negotiate contracts and IP policy with all parties at the beginning of a project. The most important message to take home is that communication early and often is key.

References

Cattanach, R., & Bellavia, C. (2017). Shareholders' agreements. In C. Lovrics (Ed.), *Startup law 101: A practical guide* (pp. 39–47). Toronto: LexisNexis Canada.

Graff, M. (2017). Intellectual property overview. In C. Lovrics (Ed.), *Startup law 101: A practical guide* (pp. 295–312). Toronto: LexisNexis Canada.

Innovations & Partnerships Office. (2018). *Inventor's guide to technology transfer* (Vol. 1). Toronto: University of Toronto. [PDF file]. http://www.research.utoronto.ca/wp-content/uploads/2018/04/18-1-Guidebooks-Inventors_FINAL.pdf.

Chapter 46
Case Study: Managing Intellectual Property with an Institution

Richard McAloney

The Challenge

Commercializing research from a university can bring great benefit to society. Your invention, know-how, and secrets make up some of your key intellectual property (IP) and ultimately define what makes you different from your potential competitors. The first step in the commercialization process in a university setting is to understand intellectual property and ownership. This can be quite clear if the invention is patentable and a patent has been filed but becomes a little murky when there is no patent involved (examples include software, expertise, and trade secrets). A clear understanding of IP ownership is required to progress through the Product Innovation Pathway (PIP). The objective of this case study is to set guidelines around working with your institution. Information was gathered through an interview with the researcher that currently leads the startup. The parties involved are kept anonymous. Each case is unique, so consider these discussions a negotiation with flexibility in the terms. There is no one-size-fits-all deal. This case study explores how researchers worked with an institution with an institution-owned IP policy that led to the creation of a company as the commercialization path. The salient points are examined to provide guidance for those embarking on this process highlighting the importance of relationships and negotiation skills. There can be significant consequences if not done right (Mercer, 2018).

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Description of Case Study

This case covers the PIP from level 1 to 3 just as the team was ready to test their product in a real-world setting and establish a start-up company. The company this case study is referring to will remain anonymous, and the specifics of the technology won't be disclosed other than to highlight that it is an assistive technology to help people remain independent. The decision to commercialize through a startup involved lengthy discussions with a range of advisors to determine a strategy. Engagement with the institution and filing of invention disclosures should be completed upon invention ([PIP] Step 1). Leaving it to the last minute could result in considerable hurdles that cause you to miss significant commercial opportunities.

The researcher was familiar with the institutions' IP policy, which is not always the case. Work was performed at the institution and funds were administered through the university. The researcher approached the IP office at the institution on instruction from the Principal Investigator. Invention disclosures were completed that included an overall description of the work, software, hardware, system specifications, and initial testing. They performed an extensive review of the patent literature and what was publicly disclosed. Based on their findings and the current understanding of the market, it was determined that patent protection was not likely possible or required. Hence, the IP consisted mostly of software code copyright, know-how, and trade secrets.

The discussions between the university and researchers highlighted the following issues:

- How was the research funded?
- Who performed the work (inventors)?
- Where was the work performed?
- Were funds administered through the university?
- What university resources were used?
- What was done and what may be IP?
- Information on the market?
- Commercialization strategy (e.g., license IP vs. startup).

The institution began with an offer of 25% royalty on sales, terms they likely deal with regularly. For a pre-revenue startup, this was not feasible. The research institution did an independent analysis of the market and decided not to attempt to license the IP. Discussions continued for 1.5 years until terms were agreed upon. There were a lot of changes in this time (business strategy, market information, company funding, etc.), so it was crucial that the parties communicated frequently, revisiting the above points as new information arose. The parties got to the point where the company offered that the institution take a 2.5% equity stake in the startup as compensation. Upon further investigation of the licensing potential, the institution ultimately agreed to take no stake in the company and make no claims on the existing IP. The software that had been developed was left with the institution. There is room for negotiation in this process, so be sure to develop negotiation and communication skills (Fisher & Ury, 2007; Goleman, 2006; Patton, Ury, & Fisher, 2014).

Outcomes and Impact

This case demonstrates that the negotiations to clarify IP ownership and compensation can be complex and lengthy even when there is no patent involved, but can be achieved to the satisfaction of both parties. Overall it is a win-win scenario when a technology moves from the university setting to impact the lives of those who need it. Subsequent to the outlined negotiation, the start-up company completed development, supports employees, raised government funding, established global partnerships, and generates revenue from sales. This is an example of successful commercialization of research that is a product on the market to help people gain independence in their daily life at home and in long-term care facilities. It should also be noted that cases like this of student commercialization successes inspire the next generation and help to inform the institution on the needs and operations of a startups.

Key Messages

- Commercializing in a university setting requires careful consideration of the ownership of the IP generated from research.
- Communicate early and often with the IP office for a smoother process, and develop your negotiation skills.
- There are no standard terms for a deal, so consider it a negotiation. Build strong relationships and develop your communication and negotiation skills.
- Set a clear timeline when creating a startup, and delineate times of university research versus company work. This begins with using separate notebooks and locations as a best practice.
- Don't be intimidated and don't give up! Be proactive and push the agenda to avoid lengthy delays.

Project Details and Team Researchers typically expect to see standard terms with respect to IP ownership and compensation. Out of the hundreds of cases of commercializing university IP that I have witnessed, the process and result are almost always different. Although the identities of the parties of this case study have been withheld the intent is to provide helpful guidance for your expectation of the process and how you prepare for the discussion. The team consisted of a professor and student commercializing work from the lab. Depending on the institution's IP policy, it can be more challenging in an institution-owned scenario if the parties don't have the same strategy in mind. It always helps to understand and align the vision and interests.

References

Fisher, R., & Ury, W. (2007). *Getting past no: negotiating in difficult situations*. New York: Bantam Dell.

Goleman, D. (2006). *Emotional intelligence*. New York: Bantam Dell.

Mercer, G. (2018, September). University of Waterloo sues startup in patent dispute. *TheRecord.com*. https://www.therecord.com/news-story/8933773-university-of-waterloo-sues-startup-in-patent-dispute/.

Patton, B., Ury, W., & Fisher, R. (2014). *Getting to yes: Negotiating agreement without giving in*. New York: Penguin Books.

Chapter 47
How to Implement an Integrated Knowledge Mobilization Approach

Dorina Simeonov, Karen Kobayashi, and Amanda Grenier

The Challenge

Knowledge mobilization (KM) is about getting the right information to the right people in the right format at the right time, so as to influence decision-making by individuals. These individuals can be older adults, caregivers, or other key stakeholders such as healthcare providers or policy makers (Simeonov, Kobayashi, & Grenier, 2017). In this chapter we argue that *integrated knowledge mobilization*, where there is a two-way exchange between stakeholders that is integrated into all steps of a project, is needed. The challenge is that without effective two-way KM, there is an estimated 17-year gap between a request for research funding and when the results are put into practice in a real-world setting (Morris, Wooding, & Grant, 2011). Furthermore, for every $1 spent on new discoveries, $0.01 is spent on sharing the findings (Farmer et al., 2008). With integrated KM and dedicated resources towards implementation, the evidence-practice gap can be significantly decreased.

This chapter defines the concept of integrated KM and provides a step-by-step process for applying KM principles in research. The first step is identifying your audience and setting the ground work for meaningful engagement of relevant stakeholders. Next is refining your research questions and key messages. The third is defining your KM goals and the fourth is applying KM strategies. Finally, the fifth

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is evaluating your approach to ensure success. As you will learn, this is not a linear process. Examples of tools and tips are provided throughout this chapter.

Key Ideas

What Is Knowledge Mobilization?

Knowledge mobilization is connecting people with people, and people with evidence (Simeonov et al., 2017). Terms like KM, knowledge translation, and knowledge exchange are often used interchangeably. They all focus on the flow of knowledge, ideas, and innovations between researchers and stakeholders with the aim of creating change and ultimately social and/or economic impact. KM is typically used in the United Kingdom, whereas knowledge translation is often used in Canadian health research. However, as has been discussed in this book, the common view of knowledge translation as a one-way linear flow of information from knowledge producers to knowledge consumers is too simplistic. KM is a dynamic and integrated activity. Although it can be closely related to commercialization and communication activities, for the purposes of this book, it is considered separately to emphasize its importance (see Table 47.1 for examples of the differences among knowledge mobilization, commercialization, and communication) (Barwick, Phipps, Myers, Johnny, & Coriandoli, 2014).

The focus of this chapter is about the creation and communication of *knowledge products* as opposed to technologies that require commercialization or public communication activities. Knowledge products focus on sharing ideas and information. Examples include public health fact sheets, policy briefs, best practice guidelines, technology product pamphlets, and care model manuals. While the commercialization of technologies is explored elsewhere in this book, it is argued in this chapter that the same kind of entrepreneurial thinking and action is required with knowledge products. For example, information needs to be *packaged* and *disseminated* in a manner that can be similar to commercial products and continues to follow the negotiated process of integrated KM where stakeholder engagement is key.

Table 47.1 Differences among knowledge mobilization, commercialization, and communication

Knowledge mobilization	Commercialization	Communication
• KM plan, knowledge products (e.g., article, policy brief, video, infographic) • Engagement with government and/or community partners, older adults, and caregivers	• Business plan • Engagement with government, industry, and/or community partners	• News releases, interviews, social media • Engagement with the media (radio, television, newspapers), government, community partners, older adults, and caregivers

Identifying and Engaging Your Audience from the Beginning

An integrated approach to KM engages all stakeholders in the co-production of and communication of knowledge from the beginning of any research project through to the end. Integrated KM is fundamental to the approach in this book as we consider involving stakeholders as partners in the project and co-production where knowledge users are also knowledge producers. Integrated KM also uses evidence and evaluation across the process it is trying to inform. In a study of eight health policy-making processes in Canada, only one had citable health services research used in all steps of the policy-making process (Lavis et al., 2002). How you can inform the policy process using your research evidence is covered in Chap. 39.

While there are always going to be practical limitations to the participation of all stakeholders in a project, this is an area in which the researcher community particularly struggles due to a lack of targeted resources and tools to facilitate meaningful engagement. As you read this chapter, there is practical advice for researchers preparing to engage in the process of integrated KM. Creating and implementing an integrated KM plan is an iterative process that requires dedicated time and resources. Table 47.2 presents a summary of the key components and questions involved in this process.

As you continue to refine your integrated KM plan, making the goals and outputs of your project explicit and getting stakeholders to agree on a mutual plan will help everyone to work together effectively. However, it is important to stay flexible as project aims may change over time. For example, technological change or new political priorities may move the goalposts for the project, or the team may encounter unanticipated obstacles to their progress. Building in buffer time into your timelines and project management processes is one way of safeguarding against this and ensuring that you achieve your KM goals. The remainder of this chapter will outline five iterative steps for implementing and integrating a KM approach into your research.

Table 47.2 Summary of the key components of knowledge mobilization

Steps 1 and 2: KM plan	Step 3: KM goals	Steps 4 and 5: KM strategies
• Plan from the beginning • Who is your audience? For example, policy makers, older adults, caregivers, clinicians • What is the applicability of your findings to each audience?	• Do you want to inform people about a new product or practice? • Do you want to change behaviors of older adults, caregivers, or clinicians? • Do you want to contribute to policy change?	• What strategies will you use beyond a publication and/or conference presentation? • How will you evaluate their effectiveness? • How will you sustain your KM activities in the long term?

Step 1: Identify Your Audience—Who Needs to Be Involved in Your Project?

- Identify project partners (individuals and organizations) that could be involved in your project, and invite them to discuss their potential role(s) and/or level of involvement.
- Identify your audience or knowledge users—who needs the product or the outputs of this project? Are you including key knowledge users on your project team? If so, invite them in from the beginning.
- What mechanisms will the project adopt to ensure that stakeholders are meaningfully involved in all aspects of the project and at all steps?

Step 2: Refine Your Message—What Message Is Your Audience Looking for?

- What do you anticipate learning?
- What did you learn?
- What key finding(s) need to be shared?
- Who is the most appropriate audience for these lessons or findings?

Information needs to be made accessible, and researchers need to consider and *know* their audience. For example, considering application to a particular population group, information on healthy living for older Chinese immigrants needs to be presented and communicated in ways that are accessible to this audience. A new healthcare practice may need training resources to support its adoption. Chapter 35 highlights some of the ideas around effective communication.

Box 47.1 Integrated KM to Reduce the Rate of Injuries in Canada
Parachute is a Canadian nonprofit organization focused on injury prevention in Canada. The integrated KM approach involves synthesizing evidence and creating and disseminating injury prevention strategies. For Parachute, the creation and sharing of knowledge among researchers, key stakeholders, and the public is a dynamic process taking place across the implementation of an integrated KM approach. Commitment to this approach is reflected in three of their six strategic priority areas, which exemplifies that integrated KM must be built into not only an organization's practices but also their policies and overall strategy. Parachute is a leader in the injury prevention field when it comes to KM. To read more about their approach and success, download the *Knowledge Translation Professional Certificate*™ *Casebook* (Barwick, 2018) or visit Parachute's website at http://www.parachutecanada.org/.

Aligning Project Goals with KM Strategies

Once you have defined your audience and co-created a common research question, you need to define your KM goals and strategies (Simeonov et al., 2017). Although we are presenting this process in a linear way here, it is important to note that these steps are iterative and ongoing. For example, once you define your KM goals, you may realize you need to go back and invite a key stakeholder to the table that is missing or reframe the research question you are asking.

Step 3: Define Your KM Goals—What Is the Real-World Impact You Want to Make?

- Is your intent to generate awareness and interest, create practice or behavioral change, or contribute to policy change?
- Based on initial work with stakeholders and partners, what is the best way to inform research and develop a knowledge product? How are findings and products working towards real-world impact? Are there mechanisms that you can leverage to share information? What formats would best communicate the knowledge and to which audiences?

Step 4: Use KM Strategies That Move Beyond Traditional Academic Outputs

Researchers typically work within structures where publications and conference presentations are the key vehicles for knowledge dissemination (and the key metrics on which researcher productivity is assessed). Often academic papers include recommendations to inform policy makers or the public about key results, but there are no specific strategies about how to proceed. Further, academic papers can sometimes use a structure and jargon that cannot be readily understood by general audiences. If research findings are to change behavior and ultimately create social and economic impact, it is important to present this information in ways that allow for their consumption by multiple audiences. Examples of KM strategies include but are not limited to (Barwick, 2008, 2013; Simeonov & Moreno, 2017a):

- In-person workshops that can bring stakeholder representatives together to discuss research results. This approach can be useful in generating buy-in and commitment to using and disseminating the research results through various stakeholder networks. For example, *individual champions* (individuals from the public or representatives from government or nonprofit organizations) can share outputs with key networks.
- Media press releases are useful in connecting with broadcast, digital, and print media. Developing connections with your organization's communications department and reporters in national and local media may facilitate prioritized

coverage if a research finding becomes news worthy. Read more about engaging media in Chap. 35.
- Social media such as the use of Twitter and Facebook has become a major outlet for connecting with target audiences and increasing the chances that your research is read and acted upon. Read more about social media as a tool in Chap. 35.

Importantly, a combination of these strategies may be more effective than single strategies, especially when you are targeting multiple audiences with unique information needs.

Box 47.2 The Knowledge Mobilization Toolkit
Numerous KM toolkits, templates, and approaches can be used to share information (see the finding support section of this chapter). The key is to ensure that you are adapting the tools for your project's purpose.

The Ontario Centre of Excellence for Child and Youth Mental Health created the KM toolkit with the goal of making evidence understandable and useful for practitioners and policy makers and to improve outcomes for children, youth, and families. This team recognized the need for integrated KM where engagement, end-user participation, and striving for real-world impact are key components for success. Their KM toolkit will help you plan for different ways to share your knowledge. See the Ontario Centre of Excellence for Child and Youth Mental Health (2014) at http://www.kmbtoolkit.ca.

Evaluating Your Integrated KM Approach

A comprehensive integrated KM approach is incomplete without an evaluation plan. It is important to measure and track whether the project's KM goals are being accomplished. Increasingly, evaluation requires a nuanced approach, using mixed methods and multiple indicators to assess impact. For example, a project that requires the development of trust relationships with a group of older adults as a first step (e.g., with refugee older adults) will require researchers to construct a different timeline and consider a different set of indicators of impact compared to a research study on the experiences of older adults in the general population. In Step 5, teams need to *develop an evaluation plan* that includes metrics and indicators reflective of the research objectives, methodological approach, activities, and outcomes of the project. This may include both quantitative and qualitative measures. Examples of qualitative indicators of impact include (Barwick, 2008, 2013; Simeonov & Moreno, 2017b):

- Knowledge dissemination (e.g., testimonials, interviews, quotes from stakeholders, participants at events, or online followers).

- Practice or service change (observed changes, reported changes, intentions to change, and/or impact of changes made).
- Changes in language or practice such as a shift from language that is considered stigmatizing or knowledge about a hidden or unrecognized population.
- Informing policy (e.g., intent to use knowledge in policy and/or decision-making, knowledge is integrated into policy, new policy, or legislation).
- Case study of outstanding work or achievement.

Examples of quantitative impact metrics include (Barwick, 2008, 2013; Simeonov & Moreno, 2017b):

- Knowledge dissemination (number of nonacademic dissemination activities in the following mediums: print [e.g., magazines, newspapers]; digital; face-to-face [e.g., workshop, course, training session, rounds, knowledge café]; TV and radio interviews; number of policy briefs provided to government and nongovernmental organizations; website or other online presence).
- Stakeholder- and end user driven research (number of stakeholders involved in your research as advisory board members; number of presentations that involved older adults and/or caregivers; community organizations, industry members, policy makers).
- National and international leadership (number of international collaborators involved in the project; number of invited expert presentations, meetings, keynotes, etc.)
- Reach indicators (number distributed, requested, downloaded, media exposure).
- Usefulness indicators (number of times read and/or browsed).
- Use indicators (number of who intend to use, number of who are adapting the information, number of who are using it to inform policy/advocacy/enhance programs or research).
- Partnership indicators (number of products/services developed or disseminated with partners, number or type of capacity building efforts).

Product Innovation Pathway Model

As mentioned above, KM is not a simple linear process. Although it involves working closely and constructively with stakeholders towards a common agenda and impact, the path to the end goal(s) is often a meandering one with numerous switchbacks and crossroads (Table 47.3).

Finding Support
Here are some useful KM resources:

- Melanie Barwick's Knowledge Translation Training and Tools. Check out the Casebook for successful examples of KM and the template for use in your research. http://melaniebarwick.com/training.php.

Table 47.3 Product Innovation Pathway (PIP) model—integrated knowledge mobilization

PIP level	PIP description	Key activities
1	Innovative ideas	Involve stakeholders in the initial development of ideas—discussions and workshops are invaluable in getting their input and buy-in. Many of the ideas in transdisciplinary working are important at this step and ideas need to be critically explored and evaluated.
2	Planning	Involve stakeholders in the objective setting and decision-making. Align the project as closely as possible to the various (and possibly competing) aims of the stakeholders. Developing an integrated KM plan is crucial at this step to define goals and strategies for knowledge co-creation and sharing.
3	Development	Engaging stakeholders as you finalize your KM goals and strategies is key to securing long-term buy-in. This engagement will help to tackle issues that might be encountered and also make sure the project continues to be aligned with their needs and objectives. Co-production approaches and methods are good tools to consider here.
4	Testing in real-world environment	This step is about ensuring your key messages and KM strategies are meeting the needs of your audience(s). Evaluate the results and outcomes of the integrated KM plan with stakeholders, and refine messages as needed. Here is where you may need to go back to Step 3 to refine KM strategies being used. You may also explore possible pathways and barriers to adoption and course correct accordingly.
5	Outcomes and impact	Working towards impact may require continuing stakeholder engagement long after a project has *officially* come to an end especially if a key stakeholder organization has taken on the sustainability of the change and impact you were aiming for. This can be challenging and requires commitment to work with stakeholders to ensure long-term impact. Having developed strong relationships with stakeholder groups early in the project may ensure their later buy-in and commitment to adopt new solutions and to continue evaluating outputs and outcomes. Demonstrate impact of your KM strategy using qualitative and quantitative indicators and metrics.

- Ontario Centre of Excellence for Child and Youth Mental Health's Knowledge Mobilization Toolkit. http://www.kmbtoolkit.ca/.
- If you are a health researcher in Canada, review the Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. http://www.cihr-irsc.gc.ca/e/45321.html.
- Achieving Research Impact: The Co-Produced Pathway to Impact (CPPI) Framework for Planning and Evaluation of Research, KT, Commercialization [Free Online Course]. https://www.udemy.com/achieving-research-impact/.
- Bayley, J. E., & Phipps, D. (2017). Impact Literacy Workbook. https://www.emeraldpublishing.com/resources/impact-literacy-workbook/.

Key Messages

- Knowledge mobilization needs to be integrated throughout your project by engaging stakeholders at each step and from beginning to the end of the project.

- Creating and implementing an integrated KM plan is an iterative process that requires dedicated time and resources to develop relationships and meaningful engagement with multiple stakeholders.
- Evaluating your integrated KM approach is vital to assessing progress towards your goals and the effectiveness and/or impact of your KM strategies.

References

Barwick, M. (2008). *Knowledge translation planning template*. Toronto: The Hospital for Sick Children.

Barwick, M. (2013). *Knowledge translation planning template*. Toronto: The Hospital for Sick Children.

Barwick, M., Phipps, D., Myers, G., Johnny, M., & Coriandoli, R. (2014). Knowledge translation and strategic communications: Unpacking differences and similarities for scholarly and research communications. *Scholarly and Research Communication, 5*(3), 0305175. http://src-online.ca/index.php/src/article/view/175/345.

Barwick, M. A. (2018). *The knowledge translation professional certificate (KTPC) casebook: Building KT friendly organizations in healthcare and beyond* (Vol. 1). Toronto: The Hospital for Sick Children.

Farmer, A. P., Légaré, F., Turcot, L., Grimshaw, J., Harvey, E., McGowan, J. L., & Wolf, F. (2008). Printed educational materials: Effects on professional practice and health care outcomes. *The Cochrane Database of Systematic Reviews, 3*, CD004398. https://doi.org/10.1002/14651858.CD004398.pub2

Lavis, J. N., Ross, S. E., Hurley, J. E., Hohenadel, J. M., Stoddart, G. L., Woodward, C. A., & Abelson, J. (2002). Examining the role of health services research in public policymaking. *The Milbank Quarterly, 80*(1), 125–154. https://doi.org/10.1111/1468-0009.00005

Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: Understanding time lags in translational research. *Journal of the Royal Society of Medicine, 104*(12), 510–520. https://doi.org/10.1258/jrsm.2011.110180

Simeonov, D., Kobayashi, K., & Grenier, A. (2017). *A resource for knowledge mobilization in aging and technology*. Toronto: AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence). http://agewell-nce.ca/research/crosscutting-activities.

Simeonov, D., & Moreno, L. (2017a). *Integrating knowledge mobilization and commercialization innovation workshop template—Project Partners, Goals and Strategies [Internet]*. Toronto: AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence). https://agewell-nce.ca/wp-content/uploads/2018/09/AGE-WELL-Innovation-Workshop-Worksheets-Project-Partners-Goals-and-Strategies.pdf.

Simeonov, D., & Moreno, L. (2017b). *Integrating knowledge mobilization and commercialization innovation workshop template—Project Evaluation Plan*. Toronto: AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence). https://agewell-nce.ca/wp-content/uploads/2018/09/AGE-WELL-Innovation-Workshop-Worksheets-Project-Evaluation-Plan.pdf.

Chapter 48
Learning Activity: Embedding Healthcare Technologies in Real-World Contexts—Developing the Scale-Up, Spread, and Sustainability of Assistive Technologies in Health Systems

Karen M. Kobayashi, Amanda Grenier, and Igor Gontcharov

The Challenge

Over the past few years, the development of innovative healthcare solutions, such as assistive technologies (ATs), has gained significant momentum and is viewed as an important potential contributor to enhancing healthy aging and relieving the burden of the oftentimes premature use of acute care services (Honeyman, Dunn, & McKenna, 2014). However, evidence for successful implementation of AT programs is sparse, especially for those that require major changes in organizations or the wider system because of the combined problems of nonadoption and abandonment by individuals as well as the difficulties associated with its scale-up and spread (Sanders et al., 2012). There is a gap in our knowledge concerning the challenges facing sustainable implementation and the key supportive factors that enhance success.

Overview of the Activity

This learning activity explores an emerging approach, the nonadoption, abandonment, scale-up, spread, and sustainability (NASSS) framework (Greenhalgh et al., 2017, 2018) that was developed to provide an "evidence-based, theory-informed,

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and pragmatic framework to help predict and evaluate the success of a technology-supported health or social care program" (2017, p. 1). In the activity, participants are asked to respond to a set of questions on the AT or other health innovation in seven domains (Greenhalgh et al., 2017): (1) the condition; (2) the technology; (3) the value proposition; (4) the adopter system (healthcare professionals, older adults, caregivers); (5) the organization(s); (6) the wider context; and (7) the emergence over time. The two objectives of the activity are (1) to help participants orient to the NASSS framework and learn about its potential for a better understanding of the implementation context of emerging innovative solutions and (2) to provide preliminary feedback about the likely challenges and opportunities for successful implementation.

Doing the Activity

This activity should be done in a group of 5–6 people.

Step 1: The group should invite a group member or an external expert, organization, or company to make a short presentation on a chosen solution (AT, policy, service, etc.). The presentation should provide an overview of the solution as well as information on how it was developed and the proposed context in which it will be used. The presentation should be a "pitch," outlining the potential benefits to users and to policy makers and service providers.

Step 2: The group should discuss the AT in terms of the seven NASSS domains.

Domain 1: What are the key characteristics of the condition or health and/or social care need the solution is intended to address?

- Is the condition well understood and well described, or is it more ambiguous and complex?
- Does the condition affect most people in the same way, and does it have a predictable course of progression?
- Is the end-user group likely to be able to adopt and utilize the solution and/or technology effectively?
- Is the condition significantly affected by the sociocultural and/or religious context?
- Is affordability an issue?

Domain 2: What are the key characteristics of the solution?

- Is it easily obtainable and dependable?
- Is it designed in a way that is easy to use and is unlikely to require a lot of technical support?
- Is the solution easy to understand or use?
- Does it fit with how the condition is normally managed?

Domain 3: Is the solution "worth developing in the first place—and for whom it generates value" (Greenhalgh et al., 2017, p. 11). Think about both the *supply-side* value (i.e., is it something the developers or service providers can expect a return on investment?) and *demand-side* value (what outcomes can patients and the health system expect?):

- Does the AT have a good business case?
- Do older adults, their families, and their caregivers desire the AT? Do they think it will bring more benefits than *harms* ("hassles")?
- What evidence is there that it is cost-effective?
- What approvals would be necessary?

Domain 4: What are the barriers, challenges, and opportunities involved in the adoption and/or nonadoption of the AT by healthcare practitioners, patients, and users?

- How are healthcare practitioners likely to see the solution fitting with their current practice?
- Will users find a solution that matches their personal preferences?
- How much extra work do users perceive that the solution requires in order to adopt it?
- Is the solution likely to support or disrupt personal support networks?

Domain 5: How will health and social care systems have to adapt and/or change in order to adopt the new solution?

- Is the leadership team of the organization able to carry through the change process?
- What decision-making process is required that would lead to a budget line item?
- How much would existing routines be disrupted by the implementation?
- What resources are required to support implementation over and above the initial procurement costs?

Domain 6: How do wider health and social care contexts affect the *scaling-up* (mainstreaming), *spread* (widely transferred across local contexts), and *sustainability* (persist in the longer term) of the solution?

- Does the solution match overall organizational goals, directions, service models, etc. (in a policy context)?
- What room is there for investments in innovative solutions (fiscal context)?
- Are the key professional associations and/or occupational groups supportive of innovative solution?

Domain 7: How do the different domains interact over time, and what are the implications for the sustainability of the new solution?

- Will the nature of the condition itself change?
- Will the solution itself likely change or be replaced due to obsolescence?
- Is it likely that the overall value proposition will change over time?

- How are healthcare practitioners, older adults, and caregivers likely to change their perception and/or use?
- What is the likelihood of the main organizations and their structures and/or policies changing significantly?
- What about the larger policy context? How stable is the current system likely to be in relation to overall direction and fiscal attitude?

Learning Outcomes
After completing this activity, the following outcome is expected:

- Participants will be able to identify what challenges and opportunities currently exist that affect the adoption and sustainability of potential new technologies, products, and services.

Learning Resources
- Greenhalgh, T., Wherton, J., Papoutsi, C., Lynch, J., Hughes, G., A'Court, C., … Shaw, S. (2017). Beyond adoption: A new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *Journal of Medical Internet Research, 19*(11), e367.
- Greenhalgh, T., Wherton, J., Papoutsi, C., Lynch, J., Hughes, G., A'Court, C., … Shaw, S. (2018). Analysing the role of complexity in explaining the fortunes of technology programmes: empirical application of the NASSS framework. *BMC Medicine Complexity Series, 16*(1), 66.

References

Greenhalgh, T., Wherton, J., Papoutsi, C., Lynch, J., Hughes, G., A'Court, C., … Shaw, S. (2017). Beyond adoption: A new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *Journal of Medical Internet Research, 19*(11), e367.

Greenhalgh, T., Wherton, J., Papoutsi, C., Lynch, J., Hughes, G., A'Court, C., … Shaw, S. (2018). Analysing the role of complexity in explaining the fortunes of technology programmes: Empirical application of the NASSS framework. *BMC Medicine Complexity Series, 16*(1), 66.

Honeyman, M., Dunn, P., & McKenna, H. (2014). *A digital NHS? An introduction to the digital agenda and plans for implementation*. London: The King's Fund. https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/A_digital_NHS_Kings_Fund_Sep_2016.pdf.

Sanders, C., Rogers, A., Bowen, R., Bower, P., Hirani, S., Cartwright, M., … Newman, S. P. (2012). Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: A qualitative study. *BMC Health Services Research, 12*, 220. https://doi.org/10.1186/1472-6963-12-220

Correction to: Thinking Innovatively About Innovation Research

Andrew Sixsmith, Judith Sixsmith, Alex Mihailidis, and Mei Lan Fang

Correction to:
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The original version of this chapter was revised due to a typo in the reference section (page -16).

On pg. 16 - 2nd reference had Jen Boger's last name spelled as "Borger."

The correct reference is given below

Boger, J., Jackson, P., Mulvenna, M., Sixsmith, J., Sixsmith, A., … Martin, S. (2017). Principles for fostering the transdisciplinary development of assistive technologies. *Disability and Rehabilitation: Assistive Technology, 12*(5), 480–490.

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Glossary[1]

A

The Actor Model Refers to "a simple table that contains a comprehensive list of stakeholder types, the specific stakeholder, the role, and the particular goals within the health care setting."

Appreciative Inquiry (AI) "Is an approach that focuses on identifying what is working well, analyzing why it is working well and then doing more of it." *WhatIs.com* (2020). Appreciative inquiry (AI). https://whatis.techtarget.com/definition/Appreciative-inquiry-AI.

Assumption personas "Are based on designers' assumptions or knowledge-to-date about their users."

Autonomy "Autonomy is a term used to describe a person's or government's ability to make decisions, or speak and act on their own behalf, without interference from another party. Although it is used in many different contexts, autonomy is most often an important element of political, philosophical, and medical conversations." *Study.com* (2020), What is Autonomy?—Definition & Ethics. https://study.com/academy/lesson/what-is-autonomy-definition-ethics.html.

[1] Compiled by J. Lynn Fraser

Note: definitions/explanations in quotation marks are definitions that are from the book or are from the editors.

Definitions/explanations without numbers are from the editors.

Numbers denote the sources for the term that include external sources and sources from within the book.

Glossary terms that appear throughout the book are not assigned chapter numbers.

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B

Base of the pyramid approach "The base (or bottom)-of-the-pyramid is a term that represents the population of the world that primarily lives and transacts in an informal market economy"; "the BoP perspective relies on a hypothesis of mutual value creation; the greater the value created for those living at the BoP, the greater the value created for the venture." *Source*: London, T., The base-of-the-pyramid perspective: A new approach to poverty alleviation. http://www.pitt.edu/~mitnick/MESM10/LondonBaseofPyramidAoM08Proceedings.pdf.

Beneficence Refers to a "duty to ensure there is some benefit to the participant for their participation."

Big Brother Refers to "a way of referring to a government, ruler, or person in authority that has complete power and tries to control people's behaviour and thoughts and limit their freedom." *Source*: Cambridge Dictionary (n.d.). Big Brother. https://dictionary.cambridge.org/dictionary/english/big-brother.

Biomarker "The term 'biomarker,' a portmanteau of 'biological marker,' refers to a broad subcategory of medical signs—that is, objective indications of medical state observed from outside the patient—which can be measured accurately and reproducibly." *Source*: Strimbu, K., Tavel, J.A. (2010). What is a biomarker? *Current Opinion in HIV and AIDS*, *5*(6): 463–466.

Biomedical ethics Is "concerned with ethical issues arising within biological and medical science as well as in health care research and practice."

Bureaucratization of science (1) "*Bureaucratization of science* with new professionals emerging to facilitate the closure of the gap—*knowledge brokers*, *implementation science/knowledge specialists*, and similar intermediaries." (2) "Increasingly science is organized around larger and larger work groups that resemble small firms, with knowledge as the product. The growth of organized science raises the question of whether we also see a bureaucratic structuring of scientific work groups as predicted by organization theory, with implications for the academic credit system and scientific labor markets." *Source*: Walsh, J.P., & Lee, Y.-N. (2015). The bureaucratization of science, *Research Policy*, *44*(8): 1584–1600.

Business brief A business brief "will summarize how results of research could be developed into new business opportunities (e.g., via partner, start-up, or open source) for both profit and not-for-profit sectors. … can highlight key market opportunities or may make specific recommendations for commercial or business development."

Business model Refers to "Whenever a business enterprise is established, it either explicitly or implicitly employs a particular business model that describes the design or architecture of the value creation, delivery, and capture mechanisms it employs (Teece, 2010, p. 172)." *Source*: Teece, D.J. (2010). Business models, business strategy and innovation. *Long Range Planning*, 43(2–3), 172–194. https://doi.org/10.1016/J.LRP.2009.07.003.

Business model canvas A "business model canvas is a prudent management and lean startup for coming up with a new or available business models. It is a visual chart with elements illustrating a firm's or product's value proposition, infrastructure, customers, and finances." *Source*: Abdoun, A., Ibrahim, J. (2018). Business model canvas, the lean canvas and the strategy sketch: Comparison. (2018) *International Journal of Scientific & Engineering Research*, 9(1): 871–889. https://www.ijser.org/researchpaper/Business-Model-Canvas-the-Lean-Canvas-and-the-Strategy-Sketch-Comparison.pdf.

C

Case-control study A case-control study is a retrospective, observational research design "where participants are selected based on outcome." In health research, "case-control studies are used to identify factors that may contribute to a health condition by comparing individuals with and without the condition of interest."

Case reports In medicine, case reports "involve narrative summary of very few participants. Usually, they are based on very rare medical cases."

Challenge [in research] Is "deployment of real-world solutions. A *challenge* is not just about problems, it may be about economic opportunities and making a positive contribution to society, government an important but complex and difficult problem area that demands innovation and policy, and the economy."

Citizen science Refers to "active public involvement in scientific research." *Source*: Irwin, A., (2018, October 24). No PhDs needed: how citizen science is transforming research, *Nature*. https://www.nature.com/articles/d41586-018-07106-5.

Clients Refers to "any public members that are users or recipients of health services (e.g., patients)" or social services.

Cohort studies Refers to "observational studies that analyse longitudinal information collected over time (Hulley et al. 2013). These studies are referred as observational because the researchers do not control what interventions the study group will receive. They can be retrospective (looking back in time) utilizing already collected information from an existing database (e.g., electronic medical records [EMR]), or prospective (forward in time) that collect new information over time i.e., longitudinal (Hulley et al. 2013)." *Source*: Hulley, S.B., Cummings, S.R., Browner, W.S., Grady, D.G., Newman, T.B. (2013). *Designing clinical research* (4th ed.). Philadelphia: Lippincott Williams & Wilkins.

Collaborative relationship Is "rooted in trust, reciprocity, and diversity, where shared learning is valued" (Murray Alzheimer Research and Education Program (MAREP) [2019]). As well "both the researcher and the research participant should have opportunities to learn, grow, and receive positive benefits." Additionally, it is important to view "the relationship as more than for the sole purpose of participating in a single research project." Authentic Partnership Model described by MAREP (2019). Murray Alzheimer Research and Education Program (MAREP). https://uwaterloo.ca/murray-alzheimer-research-and-education-program/about/authentic-partnership-model.

Community-based participatory research Is collaborative research with an "emphasis on joining with the community as full and equal partners in all phases of the research process." This research approach is particularly valuable when researching with marginalized or vulnerable populations or in sensitive areas. *Source*: Holkup, P.A., Tripp-Reimer, T., Salois, E.M., Weinert, C., (2004). Community-based participatory research: An approach to intervention research with a native American community. *Advances in Nursing Science*, *27*(3): 162–175.

Cross-cultural adaptation Cross-cultural adaptation of health technologies considers the "language, culture, and context in such a way that it is compatible with the [user]'s cultural patterns, meanings, and values" (Bernal, Jimenez-Chafey, Domenech Rodriguez, 2009). *Source*: Bernal, G., Jiménez-Chafey, M.I., Domenech Rodríguez, M.M. (2009). Cultural adaptation of treatments: A resource for considering culture in evidence-based practice. *Professional Psychology*: *Research and Practice*, *40*(4): 362. https://doi.org/10.1037/a0016401.

Cross-sectional studies Refers to "types of studies that involve information collected at a single time-point. These studies are neither experimental nor longitudinal; cross-sectional studies are descriptive as they only describe some feature of the study group at a given time. The difference between case-control studies and cross-sectional studies is temporal; meaning that in case-control studies, the *outcome* of interest is determined and, therefore, is known in advance."

D

Data services Refers to "the data systems responsible for collecting, managing, exchanging, and other data-related activities that can be used to improve outcome and efficiencies of services."

Deliberative dialogue Refers to "a face-to-face method of public interaction in which small groups of diverse individuals exchange and weigh ideas and opinions about a particular issue in which they share an interest." *Source*: Guzman, J. (2019). What is deliberative dialogue? SEDL Research on Deliberative Dialogue and Public Policy. http://www.sedl.org/policy/insights/n09/1.html.

Demand-side value Refers to "what outcomes can patients and the health system expect."

Design dash Refers to a workshop whereby participants are provided with conceptual and material resources to produce various rudimentary prototypes of technological interventions using a cyclical prototyping mechanism and sketching and prototyping techniques.

Design jam Is "also known as an 'idea jam', a 'nerd jam' or simply a 'jam'—is a collaborative brainstorming activity or event, geared towards generating solutions in a fun and creative environment." *Source*: Design Jam (n.d.). *Participedia*. https://participedia.net/method/4620.

Dialogues Refers to discussions.

Digital divide Is “any uneven distribution in the access to, use of, or impact of Information and Communication Technologies (ICT) between any number of distinct groups. These groups may be defined based on social, geographical, or geopolitical criteria, or otherwise. Because of ICT high cost, its adoption and utilization is highly uneven across the globe.” *Source*: digital divide (n.d.). *Wikipedia*. https://en.Wikipedia.org/wiki/Digital_divide.

Disruptive innovation “Is about a new technology or process that significantly changes an existing market or process.” Note that “Disruption is about effect and impact, such as creating a new market or changing the way people or an organization does something.”

Dot-mocracy “Dot-voting (also known as dotmocracy or voting with dots) is an established facilitation method used to describe voting with dot stickers or marks with a marker pen.” “In dot-voting participants vote on their chosen options using a limited number of stickers or marks with pens—dot stickers being the most common. This sticker voting approach is a form of cumulative voting.” *Source*: *Wikipedia* (2020). Dot-voting. https://en.Wikipedia.org/wiki/Dot-voting.

E

Elevator speech Refers to “a clear, brief message or ‘commercial’ about you. It communicates who you are, what you’re looking for and how you can benefit a company or organization. It’s typically about 30 seconds, the time it takes people to ride from the top to the bottom of a building in an elevator.” *Source*: The thirty-second elevator speech, http://sfp.ucdavis.edu/files/163926.pdf.

Environmental scan “Is a needs assessment tool that can be utilized to inform program development tailored to the needs of the communities … can be used for strategic planning, organizational development, information management and enhancing an organization’s ability to anticipate and respond to changes in the environment. They are also used as a planning tool to strengthen public health information and technology resources, to guide regional health care reform, and to assist in planning and development.”

EQUATOR (Enhancing the QUAlity and Transparency Of health Research) Network Refers to “an international initiative that aims to improve the reliability and value of published health research literature by promoting transparent and accurate reporting and a wider use of robust reporting guidelines (http://www.equator-network.org/).”

F

Face validity Is “also called logical validity, is a simple form of validity where you apply a superficial and subjective assessment of whether or not your study or test measures what it is supposed to measure.” *Source*: Statistics how to (2020). https://www.statisticshowto.com/face-validity/.

First Nations Is "a term used to describe Aboriginal peoples of Canada who are ethnically neither Métis nor Inuit. This term came into common usage in the 1970s and '80s and generally replaced the term 'Indian,' although unlike 'Indian,' the term 'First Nation' does not have a legal definition. While 'First Nations' refers to the ethnicity of First Nations peoples, the singular 'First Nation' can refer to a band, a reserve-based community, or a larger tribal grouping and the status Indians who live in them." *Source*: Terminology (2009). Indigenous foundations.arts.ubc.ca. https://indigenousfoundations.arts.ubc.ca/terminology/.

First Nations [and] access Refers to the First Nations having access to the information and data (FNIGC 2018)." *Source*: First Nations Information Governance Centre (FNIGC). (2019). The First Nations Principles of OCAP®. http://fnigc.ca/ocap.html.

First Nations [and] control Refers to "to the First Nations control over the research at all steps of the project" (FNIGC 2018). *Source*: First Nations Information Governance Centre (FNIGC). (2019). The First Nations Principles of OCAP®. http://fnigc.ca/ocap.html.

First Nations [and] ownership Refers to "how a community or group owns their information collectively" (FNIGC 2018). *Source*: First Nations Information Governance Centre (FNIGC). (2019). The First Nations Principles of OCAP®. http://fnigc.ca/ocap.html.

First Nations [and] possession Refers to "the physical control of data as a mechanism where 'ownership can be asserted and protected' (FNIGC 2018)." *Source*: First Nations Information Governance Centre (FNIGC). (2019). The First Nations Principles of OCAP®. http://fnigc.ca/ocap.html.

Forming (1) "The forming–storming–norming–performing model of group development (Tuckman, 1965), suggests that team formations goes through necessary phases of phases in order for the team to grow, face up to challenges, tackle problems, find solutions, plan work, and deliver results." *Source*: *Wikipedia* (2020). Tuckman's stages of group development, https://en.Wikipedia.org/wiki/Tuckman%27s_stages_of_group_development. (2) In the 'forming' stage, "…most team members are positive and polite. Some are anxious, as they haven't fully understood what work the team will do. Others are simply excited about the task ahead." This stage "can last for some time, as people start to work together, and as they make an effort to get to know their new colleagues." *Source*: *Mindtools* (2020). https://www.mindtools.com/pages/article/newLDR_86.htm.

G

Generic innovations Refers to "innovations that are so broad they could have multiple different applications in different sectors (Maine et al. 2012)." *Source*: Maine, E., Lubik, S., Garnsey, E. (2012). Process-based vs. product-based innovation: value creation by nanotech ventures. *Technovation*, *32*(3–4): 179–192. https://doi.org/10.1016/j.technovation.2011.10.003.

H

Habermasian Jürgen Habermas's "theoretical system is devoted to revealing the possibility of reason, emancipation, and rational-critical communication latent in modern institutions and in the human capacity to deliberate and pursue rational interests." *Source*: Fiorini, R.A., "Evolutive information in the Anthropocene Era." In Dodig-Crnkovic, G., Burgin, M., *Philosophy and methodology of information*: *The study of information in a transdisciplinary perspective* (pp. 201–263). New Jersey: World Scientific. https://doi.org/10.1142/9789813277526_0011.

Hard copy Refers to print form.

Hard to reach [populations] Are "groups of persons who are difficult to find and often even more challenging to engage … may include vulnerable populations, such as persons with low socioeconomic status, victims of abuse and trauma survivors, persons with complex health impairments or those nearing end of life, and populations at higher risk of discrimination or stigma (e.g., opioid substance users, members of the LBGTQ+ (lesbian, gay, bisexual, transgender, queer, and questioning) community, Indigenous peoples)."

Health innovation Refers to "any advance in the science or practice of health care or health science that advances our knowledge and improves the outcomes of better individual and population health and well-being."

Health systems Refers to "any systems that are involved in the oversight of the care for the clients and providers, for example hospitals and nursing homes."

Health Technology Assessment (HTA) Are "systematic evaluations of technologies using evidence to consider the direct and unintended costs and consequences of the technology (International Network of Agencies for Health Technology Assessment 2006)." *Source*: International Network of Agencies for Health Technology Assessment (INAHTA) (2006). HTA Glossary. http://htaglossary.net/HomePage.

Hidden populations Refers to "those who do not wish to be found"; "differ from hard to reach populations. Persons belonging to a hidden population often highly value their privacy and may purposefully conceal their identity from researchers."

Hierarchy of evidence Note: The concept of hierarchies of evidence is a contested notion. "Evaluation of health care interventions generally follows a framework called 'hierarchy of evidence' that was developed for biomedical research in 1995 (Guyatt et al., 2002, pp. 10–12). This framework ranks the evidence by the types of studies that were used to generate the evidence (see Table 19.1). While the hierarchy of evidence framework was not specifically developed for technology research, its core principle can still be generalized to evaluating health technology interventions, since health technology solutions are prone to similar biases as biomedical interventions." *Source*: Guyatt, G., Rennie, D., Meade, M., Cook, D. (2002). *Users' guides to the medical literature*: *A manual for evidence-based clinical practice* (Vol. 706). Chicago: AMA Press.

Holistic "A holistic approach means thinking about the big picture," taking into account all aspects of the issue at hand. "Whether you're doing holistic parenting, holistic website design, or holistic medicine, know that each change you make to one part affects the whole." *Source*: Ameritech College, 6 Ways to Approach Problems Holistically. (n.d.). https://www.ameritech.edu/blog/6-ways-approach-problems-holistically/.

Human-computer interaction "Human-computer interaction (HCI) is a multidisciplinary field of study focusing on the design of computer technology and, in particular, the interaction between humans (the users) and computers." *Source*: Interaction Design Foundation. Human-Computer Interaction (HCI). https://www.interaction-design.org/literature/topics/human-computer-interaction.

I

Impact case studies Refers to a description of "how knowledge developed in a research project has produced health, service, economic, cultural or social benefits in real-world settings.

Information sheet "Will provide the general reader with a simple 'What we know' or 'How to' guide to current knowledge on a research topic or area." In research context, an information sheet informs potential participants about the aims and objectives of the research, the research process, and their involvement in it, alongside the potential benefits of the research, and the contact details of researchers.

Incremental innovation "Value, reduce costs, etc. It might make an existing product more competitive is about small improvements that will make something more efficient, add, or extend its shelf life in the market."

Infographic Refers to "a visual image used to represent data or information."

Institutional review board "Is an administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution with which it is affiliated." *Source*: Oregon State University (2020). What is the Institutional Review Board (IRB)? https://research.oregonstate.edu/irb/frequently-asked-questions/what-institutional-review-board-irb.

Integrated knowledge translation (iKT) iKT is defined as "an ongoing relationship between researchers and decision-makers" (Gagliardi et al., 2016, p.1) in the KT process, and refers to an integrated and participatory way of working whereby researchers, practitioners, and knowledge users collaborate to co-generate new knowledge that is relevant in real world settings (Battersby et al., 2017). *Source*: Gagliardi, A.R., Berta, W., Kothari, A., Boyko, J., Urquhart, R. (2016). Integrated knowledge translation (IKT) in health care: A scoping review. *Implementation Science,* 11, Article 38. doi: https://doi.org/10.1186/s13012-016-0399-1. Battersby, L., Fang, M.L., Canham, S.L., Sixsmith, J., Moreno, S., Sixsmith A. (2017). Co-creation methods: Informing technology solutions for older adults. In Jia, Z., Salvendy, G. (Eds.), Human aspects of IT for the aged population. *Aging, Design and User Experience* (pp. 77–89). New York, NY: Springer.

Intellectual property "Intellectual property (IP) refers to creations of the mind, such as inventions; literary and artistic works; designs; and symbols, names and images used in commerce." *Source*: World Intellectual Property Organization (2020). What is intellectual property? https://www.wipo.int/about-ip/en/.

Interdisciplinarity Refers to "combining different types of academic knowledge and ideas." (1) Interdisciplinarians focus on particular problem or questions that are too complex to be answered satisfactorily by any one discipline … integrate the best elements of disciplinary insights in order to generate a more comprehensive (and often more nuanced) appreciation of the issue at hand." *Source*: Szostak, R. (2015). Defining "Interdisciplinary." University of Alberta, Department of Economics. https://sites.google.com/a/ualberta.ca/rick-szostak/research/about-interdisciplinarity/definitions/defining-instrumental-interdisciplinarity.

Interdisciplinary research "Is any study or group of studies undertaken by scholars from two or more distinct scientific disciplines. The research is based upon a conceptual model that links or integrates theoretical frameworks from those disciplines, uses study design and methodology that is not limited to any one field, and requires the use of perspectives and skills of the involved disciplines throughout multiple phases of the research process." *Source*: Aboelela, S.W., Larson, E., Bakken, S., Carrasquillo, O., Formicola, A., Glied, S.A., Haas, J., Gebbie, K.M. (2007). Defining interdisciplinary research: Conclusions from a critical review of the literature. *Health Services Research*, *42*: 329–346. doi: https://doi.org/10.1111/j.1475-6773.2006.00621.x. https://www.hsph.harvard.edu/trec/about-us/definitions/.

Intersectionality (1) Refers to "a theoretical framework for understanding how aspects of one's social and political identities (gender, race, class, sexuality, ability, height etc.) might combine to create unique modes of discrimination." *Source*: (1) *Wikipedia* (2020). Intersectionality. https://en.Wikipedia.org/wiki/Intersectionality. (2) "An intersectional approach takes into account the historical, social and political context and recognizes the unique experience of the individual based on the intersection of all relevant grounds." *Source*: Ontario Human Rights Commission (2001). An introduction to the intersectional approach. www.ohrc.on.ca/en/intersectional-approach-discrimination-addressing-multiple-grounds-human-rights-claims/introduction-intersectional-approach.

K

Knowledge café Refers to "is a conversational process that brings a group of people together to share experiences, learn from each other, build relationships and make a better sense of a rapidly changing, complex, less predictable world to improve decision making, innovation and the ways in which we work together" *Source*: The knowledge café concept (n.d.). https://knowledge.cafe/knowledge-cafe-concept/.

Knowledge dissemination "The most common definition is the willing transfer of knowledge with the intension that it be used for education or to help implement modified or new practices. Dissemination is the interactive process of communicating knowledge to target audiences so that it may lead to change. The challenge is to improve the accessibility of desired knowledge products by those they are intended to reach. This means ensuring availability of the product to as much of the target audience as possible, and making the product comprehensible to those who receive it." *Source*: Global Institute for Water, Environment & Health (2015). Knowledge dissemination. http://www.giweh.ch/page.aspx?s=1&l=1&pg=38&md=pagedetail.

Knowledge mobilization (1) Is not merely knowledge transfer. KM: "seeks to reimagine the very relationship between science and society." It has emerged "as a means to trigger deeper structural changes, not only within academia, but in *knowledge society* in general, a society in which 'academic science' is an embedded social institution." It is "rather a process of reflexive engagement with scientific processes and social institutions *across* knowledge society in general, which involves other modalities of knowledge production, including such expansive and critical fields as alternative and independent research." (2) It is "a process of reflexive engagement with scientific processes and social institutions *across* knowledge society in general, which involves other modalities of knowledge production, including such expansive and critical fields as alternative and independent research." Refers to "connecting people with people, and people with evidence (Simeonov et al. 2017)." *Source*: Simeonov, D., Kobayashi, K., Grenier, A. (2017). A resource for knowledge mobilization in aging and technology. Toronto: AGE-WELL NCE (Aging Gracefully across Environments using Technology to Support Wellness, Engagement and Long Life Network of Centres of Excellence) (2020). http://agewell-nce.ca/research/crosscutting-activities.

Knowledge products Are products such as policy briefs, reports, guidelines, models of good practice, standards and recommendations, and other forms of information for public consumption. Other examples include the following: "Text documents (books, journals, periodicals, essays, poetry, etc.); Recorded music; Films and television programs; Art (paintings, sculpture, installations, etc.); Flags, logos, branding, trademarks, trade dress; Legal documents (contracts, acts, writs, etc.); Software." *Source*: Dorian Taylor, make things. Make sense (2009). Knowledge product. https://doriantaylor.com/lexicon/knowledge-product.

Knowledge society Refers to "a society in which 'academic science' is an embedded social institution. That is, where any knowledge production and sharing that takes place within academic settings is also enabled and constrained by broader social forces." It also refers to "a knowledge society, removes existing barriers that block or slow down public participation and knowledge flows, and engages in ongoing meaningful discussions and innovation."

Knowledge translation "Is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the nature of the research and the findings as well as the needs of the particular knowledge user (Graham, 2010)." *Source*: Canadian Institutes of Health Research (2016). About us. https://cihr-irsc.gc.ca/e/29418.html#2.

Knowledge transfer The "traditional view of *knowledge transfer or translation* is about communicating a message from academia to other fields of research, sectors of the economy, policy makers, and the public." Is a term "used to encompass a very broad range of activities to support mutually beneficial collaborations between universities, businesses and the public sector." *Source*: University of Cambridge (2009). What is knowledge transfer? https://www.cam.ac.uk/research/news/what-is-knowledge-transfer.

Knowledge user Refers to "an individual who is likely to be able to use the knowledge generated through research to make informed decisions about health policies, programs and/or practices. A knowledge-user's level of engagement in the research process may vary in intensity and complexity depending on the nature of the research and his/her information needs. … can be, but is not limited to, a practitioner, policy-maker, educator, decision-maker, health care administrator, community leader, or an individual in a health charity, patient group, private sector organization, or media outlet." *Source*: Canadian Institutes of Health Research (2016). About us. https://cihr-irsc.gc.ca/e/29418.html#2.

M

Mainstreaming Mainstream. Refers to "a prevailing current or direction of activity or influence." *Source*: *Merriam Webster* (2020). https://www.merriam-webster.com/dictionary/mainstream.

Matters of care "Contests the view that care is something only humans do, and argues for extending to non-humans the consideration of agencies and communities that make the living web of care by considering how care circulates in the natural world." *Source*: ResearchGate GmbH (2020). Abstract. Matters of care: Speculative ethics in more than human worlds. https://www.researchgate.net/publication/321704484_Matters_of_care_Speculative_ethics_in_more_than_human_worlds.

Memorandum of understanding "Is a type of agreement between two (bilateral) or more (multilateral) parties. It expresses a convergence of will between the parties, indicating an intended common line of action. It is often used either in cases where parties do not imply a legal commitment or in situations where the parties cannot create a legally enforceable agreement. It is a more formal alternative to a gentlemen's agreement." *Source*: *Wikipedia* (2020). Memorandum of understanding. https://en.Wikipedia.org/wiki/Memorandum_of_understanding.

Minimal risk Refers to "risk that is no more than what people may experience in daily life."

Mobile health (mHealth) Refers to "the application of mobile technology for the provision of healthcare support to patients and care providers."

Moonshot ideas "Moonshot thinking is when you pick a huge problem, like climate change, and set out to create a radical solution to the problem. To make this happen you have to abandon the idea of creating a 10% improvement. Instead, the focus is a solution that will bring tenfold (or 10×) improvements, or solve it altogether." *Source*: Alison E. Berman (2016). How to invent radical solutions to huge problems: A guide to moonshot thinking. https://medium.com/singularityu/how-to-invent-radical-solutions-to-huge-problems-745d8207649a.

Multidisciplinary "Focuses primarily on the different disciplines and the diverse perspectives they bring to illustrate a topic, theme or issue. A multidisciplinary curriculum is one in which the same topic is studied from the viewpoint of more than one discipline. Frequently multidisciplinary and crossdisciplinary are used as synonyms describing the aim to cross boundaries between disciplines." *Source*: International Bureau of Education (2020). Multidisciplinary approach. http://www.ibe.unesco.org/en/glossary-curriculum-terminology/m/multidisciplinary-approach.

N

Narrative reviews "Are informal, often unsystematic, and use subjective methods to collect and interpret information. This type of review is usually not considered methodologically rigorous. Details of the methods that relate to searching, data synthesis, and quality appraisal are not usually described. Findings are often summarized subjectively and narratively. Narrative reviews are more prone to bias and overestimate the value of some studies although they are quick to perform and are known to be performed by experts in the field."

Need statement "Presents facts and evidence to support the need for the new project, program, device, or related intervention that you are proposing."

Needs statement "A needs statement establishes the rationale for a project by clearly identifying the gap or problem within a specific community. A needs statement should determine the focus an organization will take by addressing the particular needs of a specific target audience through a very distinct project. The needs statement should also explain to a funder what the community requires or what it is lacking, and defines the underlying issues the applicant is addressing. Ultimately, the needs statement should answer the questions, "What is the problem or need?" and "How do you know it's a problem?" *Source*: GrantsEdge Team (2020). The 4 fundamental features of a strong needs statement. https://www.grantsedge.com/needs-statement/.

Non-dilutive funding sources "Support research innovations and commercialization." Note that "non-dilutive funding is money that you do not need to pay back, or provide a financial return on investment. … it includes: research grants; … awards; …and government programs."

Nonparametric statistics Refers to "a statistical method in which the data is not required to fit a normal distribution. Nonparametric statistics uses data that is often ordinal, meaning it does not rely on numbers, but rather on a ranking or order of sorts." *Source*: Investopedia (2020). Nonparametric statistics. https://www.investopedia.com/terms/n/nonparametric-statistics.asp.

Norming (1) "The forming–storming–norming–performing model of group development (Tuckman, 1965), suggests that team formations goes through necessary phases of phases in order for the team to grow, face up to challenges, tackle problems, find solutions, plan work, and deliver results." *Wikipedia* (2020). Tuckman's stages of group development. https://en.Wikipedia.org/wiki/Tuckman%27s_stages_of_group_development. Norming relates the "when people start to resolve their differences, appreciate colleagues' strengths, and respect your authority as a leader." *Source*: MindTools Content Team (2020). Forming, storming, norming, and performing: Understanding the stages of team formation. https://www.mindtools.com/pages/article/newLDR_86.htm.

Paradigm (1) "A paradigm is a distinct set of concepts or thought patterns, including theories, research methods, postulates, and standards for what constitutes legitimate contributions to a field." *Wikipedia* (2020). Paradigm. https://en.Wikipedia.org/wiki/Paradigm. (2) It is "a theory or a group of ideas about how something should be done, made, or thought about." *Source*: Lombrozo, T. (2016). National Public Radio. https://www.npr.org/sections/13.7/2016/07/18/486487713/what-is-a-paradigm-shift-anyway.

Participatory Action Research (1) "Focuses on social change that promotes democracy and challenges inequality; is context-specific, often targeted on the needs of a particular group; is an iterative cycle of research, action and reflection; and often seeks to 'liberate' participants to have a greater awareness of their situation in order to take action. PAR uses a range of different methods, both qualitative and quantitative" *Source*: Institute of Development Studies (n.d.). Participant action research. Participatory Methods. https://www.participatorymethods.org/glossary/participatory-action-research. (2) "Participants are regarded as experts due to their lived experiences related to the research topic, ensuring that relevant issues are being studied…is a type of research that combines two different approaches: participatory research and action research … encourages equal involvement from researchers and participants in the research process. When participants and researchers are equal partners, the research focus and results can be more relevant to a specific community… typically involves selecting research issues related to dependence, oppression, and other inequities in need of evaluation." *Source*: Watters, J., Comeau, S., Restall, G. (2010), Participatory Action Research: An educational tool for citizen-users of community mental health services, http://umanitoba.ca/rehabsciences/media/par_manual.pdf.

Participatory design "Is an approach to design attempting to actively involve all stakeholders (e.g. employees, partners, customers, citizens, end users) in the design process to help ensure the result meets their needs and is usable…is focused on processes and procedures of design and is not a design style. The term is used in a variety of fields...as a way of creating environments that are more responsive and appropriate to their inhabitants' and users' cultural, emotional, spiritual and practical needs." *Source*: *Wikipedia* (2020). Participatory design. https://en.Wikipedia.org/wiki/Participatory_design.

Path dependence "Explains how the set of decisions people face for any given circumstance is limited by the decisions they have made in the past or by the events that they experienced, even though past circumstances may no longer be relevant….In economics and the social sciences, path dependence can refer either to outcomes at a single moment in time, or to long-run equilibria of a process." *Source*: *Wikipedia* (2020). Path dependence. https://en.Wikipedia.org/wiki/Path_dependence.

Persona "A persona is a description of a fictitious individual based on data gathered from real stakeholders (Adlin and Pruitt 2010). Personas are used in product design and development to help identify user needs and priorities. Personas can be viewed as a tool for considering how a product might be used, particularly in any potential problems one might encounter during usage. Personas are intended to promote our empathy with the people for whom who we are designing a product." *Source*: Adlin, T., Pruitt, J. (2010). *The essential persona lifecycle*: *your guide to building and using personas*. Burlington: Morgan Kauffman.

Photovoice Is an empowering qualitative research method often employed within community-based participatory research to document and reflect person's "reality." It is a flexible arts-based process that combines photography with grassroots social action. Participants include community members of all ages and status including those who are discriminated against due to language, gender, race, class, disability, etc.

Place making "Inspires people to collectively reimagine and reinvent public spaces as the heart of every community. Strengthening the connection between people and the places they share, placemaking refers to a collaborative process by which we can shape our public realm in order to maximize shared value." *Source*: Project for Public Space (2018). What is placemaking? https://www.pps.org/article/what-is-placemaking.

Policy brief "Will present an overview or results of a research project along with recommendations for action by a political body (e.g., ministry, service provider, non-government organization)."

Project briefing "The lay summary of the who, what, why, how, where, and when of a new project that is typically required by funders. …will provide an overview of the aims, objectives, and approaches of a research project."

Pomodoro Technique "Is a time management method developed by Francesco Cirillo in the late 1980s. The technique uses a timer to break down work into intervals, traditionally 25 minutes in length, separated by short breaks. Each interval is known as a *pomodoro*, from the Italian word for 'tomato', after the tomato-shaped kitchen timer that Cirillo used as a university student." *Source*: *Wikipedia* (2020). Pomodoro technique. https://en.Wikipedia.org/wiki/Pomodoro_Technique.

Positivist paradigm of research “Positivism adheres to the view that only ‘factual’ knowledge gained through observation (the senses), including measurement, is trustworthy. In positivism studies the role of the researcher is limited to data collection and interpretation in an objective way. In these types of studies research findings are usually observable and quantifiable. Positivism depends on quantifiable observations that lead to statistical analyses.” *Source*: Research methodology (n.d.). Positivism research philosophy. https://research-methodology.net/research-philosophy/positivism/.

Pre-eclampsia “Preeclampsia is a pregnancy complication characterized by high blood pressure and signs of damage to another organ system, most often the liver and kidneys. Preeclampsia usually begins after 20 weeks of pregnancy in women whose blood pressure had been normal. Left untreated, preeclampsia can lead to serious—even fatal—complications” for mother and baby.” *Source*: Mayo Foundation for Medical Education and Research (2020). Preeclampsia. https://www.mayoclinic.org/diseases-conditions/preeclampsia/symptoms-causes/syc-20355745.

Prescriptive scenario “May describe a user’s interaction with a particular system as a factual sequence of actions and/or decisions.”

Principle of non-maleficence “Do not intentionally cause harm or injury to the research participant, either through acts of commission or omission.”

Principlism “As proposed by T.L. Beauchamp and J.F. Childress, involves the moral principles of autonomy, beneficence, maleficence and justice, and dominates the traditional western framework (Beauchamp and Childress 2009).” *Source*: Beauchamp, T.L., Childress, J.F. (2009). *Principles of biomedical ethics* (6th ed.), New York: Oxford University Press.

Problem space Refers to “A mental representation of a particular problem, including initial, final and possible intermediate states.” *Source*: *Wiktionary* (2017). Problem space. https://en.wiktionary.org/wiki/problem_space.

Product Innovation Pathway (PIP) model “PIP represents different levels of product maturity—the process of moving from initial ideas towards deployment, mobilization, and adoption of a product.”

Providers Refers to “those who deliver care and services to clients…(e.g., doctors and nurses).”

Q

Qualitative methods Focus on gathering data through open-ended, verbal/conversational and visual communication between participants and researchers to better understand “what” people think and also “why” they think so.

R

Radical innovation Refers to "something that makes significant improvements to a product, process, or business model that already exists or is something completely new." It can be "about creating new industries or markets and typically comes from an entirely new technology, service, or procedure."

Randomized clinical trials "These studies are experimental in nature and involve comparison(s) of one or more intervention groups to a control group, with the assignment of a group being determined by randomization."

Realist review In a realist review, "as opposed to a judgment, about how it works…is fundamentally concerned with theory development and refinement, accounting for context as well as outcomes in the process of systematically and The focus is on understanding and unpacking the mechanisms by which an intervention works (or fails to work), thereby providing an explanation transparently synthesizing relevant purposefully selected literature."

Reflexivity By reflexivity, "we mean critical engagement with our own knowledge and practice, and the broader institutional initiatives and norms of knowledge production and sharing. Reflexivity involves a process of self-reflection and reconsideration of taken-for-granted practices of power and knowledge that exist within and across a range of settings." Also, "reflexivity in knowledge mobilization is thus an idea of conceptualizing a process of self-awareness as well as project/team awareness, experience and self-identity in practices of knowledge co-production."

Research briefing "Will provide an overview of the aims, objectives, and approaches of a research project."

Research briefing notes "Present results of a research project. Projects here refer to any academic research that has produced outputs such as new knowledge, devices, or systems."

Research output "An output is anything created by a project during its research and innovation activities. These may include scientific papers, prototypes, patents, business plans, evaluation reports, etc."

Research products Refers to "the technologies, services, toolkits and policies that will be produced through our research and implemented and used in the 'real-world.'" The term also refers to "what the project is aiming to deliver as its ultimate end output that will be utilized in the real-world. Products are tangible and require the research team to think in concrete terms." Products from research projects are broad in scope, for example: knowledge products; service products; and technology products.

Responsibility "Requires engaging with complex ethical and social questions throughout every stage of the design process. It requires that each person involved weigh-in on these issues."

Risk "Risk for potential harm to individuals or groups may be social, behavioral, psychological, physical, or economic. Risk is evaluated based on the harm's magnitude or seriousness and the probability of the harm for participants or others."

S

Safety "In the context of health technology is not just be limited to health safety (e.g., physical safety), but it should also address concerns of confidentiality, data security, system and/or technology reliability, and system and/or technology recoverability."

Sarcopenia Refers to "loss of muscle mass and strength."

Scenarios Refers to "stories of user experience: they describe a setting or situation in detail in which a person performs a sequence of actions (possibly involving other people), as well as the outcome of those actions (Carroll 2000). …scenarios can describe how or why someone does something a certain way today (i.e., a scenario of reality) and how they might do something using a potential product or service (i.e., a proposed or future scenario). …include information about the setting or situation, the person or people involved, their goals or objectives, and a *plot*—a sequence of actions or events." Scenarios can also be fictional and speculative.

Scoping reviews "Systematically assess the breadth of a body of literature in a particular research area. They are used to map key underlying concepts of the area in question and may, therefore, help to identify research gaps in existing literature. Scoping reviews differ to that of systematic reviews in that they are exploratory in nature while still aiming to maintain the same level of rigor."

Seldom heard Refers to those whose voice is often not heard in research contexts.

Service design "Is the activity of planning and organizing a business's resources (people, props, and processes) in order to (1) directly improve the employee's experience, and (2) indirectly, the customer's experience." *Source*: Nielsen Norman Group (2020). Service design 101. https://www.nngroup.com/articles/service-design-101/.

Service products "These are the delivery models and mechanisms that will allow new technologies, solutions, etc. to be provided to the user or patient."

Skin in the game "To have 'skin in the game' is to have incurred risk (monetary or otherwise) by being involved in achieving a goal. In the phrase, 'skin' is a synecdoche for the person involved, and 'game' is the metaphor for actions on the field of play under discussion." *Source*: *Wikipedia* (2020). Skin in the game (phrase). https://en.Wikipedia.org/wiki/Skin_in_the_game_(phrase).

Slide deck Refers to "a series of slides used as a visual aid during a talk; often just called a deck." *Source*: *MacMillan Dictionary* (2020). Slide deck. https://www.macmillandictionary.com/dictionary/british/slide-deck.

Snowball sampling "Is where research participants recruit other participants for a test or study. It is used where potential participants are hard to find. It's called snowball sampling because (in theory) once you have the ball rolling, it picks up more 'snow' along the way and becomes larger and larger. Snowball sampling is a non-probability sampling method." *Source*: *Statistics how to* (2020). Snowball sampling: Definition, advantages and disadvantages. https://www.statisticshowto.com/snowball-sampling/.

Stakeholders A stakeholder is any person, organization, social group, or society at large that has a stake in the phenomena under consideration.

Stakeholder landscape Breadth and variety of individuals and groups who are stakeholders regarding a particular issue. For example, "in a health care setting, such as a hospital or residential facility, you will have patients, family caregivers, nurses, health professionals, physicians, care assistants, support staff (e.g., cleaners and kitchen staff), as well as middle and senior management. In a for-profit organization, you may have owners, staff, and/or a board of directors."

Storming (1) "The forming–storming–norming–performing model of group development was first proposed by Bruce Tuckman in 1965, who said that these phases are all necessary and inevitable in order for the team to grow, face up to challenges, tackle problems, find solutions, plan work, and deliver results." *Source*: *Wikipedia* (2020). Tuckman's stages of group development. https://en.Wikipedia.org/wiki/Tuckman%27s_stages_of_group_development. (2) "Next, the team moves into the storming phase, where people start to push against the boundaries established in the forming stage. This is the stage where many teams fail." "Storming often starts where there is a conflict between team members' natural working styles." *Source*: MindTools (2020). Forming, storming, norming, and performing: Understanding the stages of team formation. https://www.mindtools.com/pages/article/newLDR_86.htm.

Structured brainstorming Refers to "the process of systematic and liberal generation of a large volume of ideas from a number of participants by encouraging each of them to volunteer their creative inputs one at a time in an atmosphere that is free of criticism and judgment from other participants." *Source*: eesemi.com (2020). Structured brainstorming. https://www.eesemi.com/brainstorming.htm.

Supply-side value "Is it something the developers or service providers can expect a return on investment?"

Systematic reviews "A review of the evidence on a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant primary research, and to extract and analyze data from the studies that are included in the review…are highly rigorous forms of reviews that aim to minimize bias, are replicable, useful for resolving controversy between conflicting findings and can provide for a reliable basis for decision-making. However, systematic reviews are both time and resource intensive."

T

Teal organization Refers to "an emerging organizational paradigm that advocates a level of consciousness including all previous world views within the operations of an organization. The concept of Teal organization refers to the next stage in the evolution of consciousness and was introduced in 2014 by Frederic Laloux in his book on *Reinventing* Organizations." *Source*: Wikipedia (2020). Teal organisation. https://en.Wikipedia.org/wiki/Teal_organisation.

Technology products "These are the interventions, systems and devices aimed at directly supporting the health of patients and consumers. Note that these may include new drugs or surgical procedures."

Technology Readiness Scale (TRL) "The TRL defines the process of innovation as a series of stages of maturity from concept to implementation."

Terms of Reference document "Outlines the organization, purpose and structure of the project, identifies the ways people can contribute and how knowledge flows around the project (Jones and Wells 2007)." *Source*: Jones, L., Wells, K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *Journal of the American Medical Association*, *297*(4), 407–410. doi:https://doi.org/10.1001/jama.297.4.407.

Traditional research methods Those methods "that have been often used in research studies and are well recognised within a field of study such as surveys or interviews and/or studios that use a single method to understanding a complex problem."

Transdisciplinary research "Is defined as research efforts conducted by investigators from different disciplines working jointly to create new conceptual, theoretical, methodological, and translational innovations that integrate and move beyond discipline-specific approaches to address a common problem." *Source*: Harvard Transdisciplinary Research in Energetics and Cancer Center (2020). Definitions. https://www.hsph.harvard.edu/trec/about-us/definitions/.

Transdisciplinary working "Where team members from different disciplines work together; across boundaries, for example an engineer and nutritionist running a technology focus group." "to engage stakeholders in all aspects of the research process rather than restrict their role to passive test subjects who only provide test-design feedback (Grigorovich et al. 2019). Another defining principle of TDW is the integration of knowledge across scientific disciplines and between academic and non-academic sectors" (Grigorovich et al. 2019). *Source*: Grigorovich, A., Fang, M.L., Sixsmith, J., Kontos, P. (2019). Defining and evaluating the effectiveness of transdisciplinary research in aging and technology. *Disability and Rehabilitation*: *Assistive Technology*, *14*(6), 533–542.

Transformational change "A shift in the business culture of an organization resulting from a change in the underlying strategy and processes that the organization has used in the past. A transformational change is designed to be organization-wide and is enacted over a period of time." *Source*: BusinessDirectory (2020). Transformational change. http://www.businessdictionary.com/definition/transformational-change.html.

Transformative research "Involves ideas, discoveries, or tools that radically change our understanding of an important existing scientific or engineering concept or educational practice or leads to the creation of a new paradigm or field of science, engineering, or education. Such research challenges current understanding or provides pathways to new frontiers." *Source*: National Science Foundation (n.d.). Definition of transformative research. https://www.nsf.gov/about/transformative_research/definition.jsp.

Transformative space Refers to "a *rethinking* of the problem area by linking diverse types of knowledges and actions, and envisioning how to mobilize resources and create new possibilities for social change (Marshall et al. 2018)." *Source*: Marshall, F., Dolley, J., Priya, R. (2018). Transdisciplinary research as transformative space making for sustainability: enhancing proper transformative agency in periurban contexts. *Ecology and Society*, *23*(3), 8. www.ecologyand-society.org/vol23/iss3/art8/#transformative.

U

Use case (1) "A technique originating from software engineering that are used for identifying and describing the interactions that take place when a system is used (Kulak and Guiney 2012)." They "focus on the goals and behaviors of the entities (including both people and machines) involved in a system while avoiding details such as the specific implementation of a technology." Also they "can be generated as a diagram which identifies the system itself, external actors (humans and other systems) which interact with the system, actions, goals, and relationships. They can also be generated in text format, which includes a description of the steps and possible outcomes of a task or interaction." *Source*: (1) Kulak, D., Guiney, E. (2012). *Use cases*: *requirements in context* (2nd ed.). New York: Addison-Wesley. (2) "Define interactions between external actors and the system to attain particular goals. There are three basic elements that make up a use case: Actors: Actors are the type of users that interact with the system. System: Use cases capture functional requirements that specify the intended behavior of the system. Goals: Use cases are typically initiated by a user to fulfill goals describing the activities and variants involved in attaining the goal." *Source*: (2) Techopedia (2014). Use case. https://www.techopedia.com/definition/25813/use-case.

V

Value chain Refers to "a set of activities that a firm operating in a specific industry performs in order to deliver a valuable product (i.e., good and/or service) for the market." *Source*: *Wikipedia* (2020). Value chain. https://en.Wikipedia.org/wiki/Value_chain.

Value proposition A "service, feature or innovation that makes a product attractive to customers (e.g., price and efficiency or overall customer experience), infrastructure (e.g., key resources, key activities, supply chain), customers (e.g., mass market, niche market), and finances (e.g., cost structure [cost driven vs. value driven] and revenue stream)." (2) "A positioning statement that explains what benefit you provide for who and how you do it uniquely well. It describes your target buyer, the problem you solve, and why you're distinctly better than the alternatives." *Source*: Skok, M. (2013). 4 Steps to building a compelling value proposition. Forbes.com. https://www.forbes.com/sites/michaelskok/2013/06/14/4-steps-to-building-a-compelling-value-proposition/#5d58e51a4695.

Valley of death "This gap between [Research and development] and real-world deployment" (Hudson et al. 2013). *Source*: Hudson, J., Khazragui, H.F. (2013). Into the valley of death: research innovation. *Drug Discovery Today*, *18*(13–14), 610–613. https://www.sciencedirect.com/science/article/pii/S1359644613000342.

Value sensitive design (VSD) Refers to "a theoretically grounded approach to the design of technology that accounts for human values in a principled and comprehensive manner. VSD addresses design issues within the fields of information systems design and human-computer interaction by emphasizing the ethical values of direct and indirect stakeholders." *Source*: *Wikipedia* (2019). Value sensitive design. https://en.Wikipedia.org/wiki/Value_sensitive_design.

Vulnerability Refers to a "person or group is considered vulnerable if they experience restrictions owing to decreased decision-making ability, autonomy, power, and opportunities or rights."

W

Wicked problems Refers to those "complex, multi-layered and almost intransigent problems." It also includes: "wicked problems in the health sector are typically unique, requiring unique creative solutions that are built from the ground up *with*, rather than *for* the people who will use and benefit from them."

Whole project management Refers to "every part of the project is seen in its relation to the whole."

World café Refers to "a methodology to enable in-depth discussions to occur by engaging a large group of cross-sectoral stakeholders in concurrent smaller group dialogues, in order to explore a single question or use a progressively deeper line of inquiry through several conversational rounds. The main difference between a world café and a knowledge café is that, during a world café, participants are required to change tables according to pre-defined time intervals, in order to review and build upon the previous discussion to generate reciprocal, critical knowledge exchange between diverse stakeholders" (Brown & Isaacs, 2002). *Source*: Brown, J., Isaacs, D. (2002). *The world café*: *Shaping our futures through conversations that matter.* Mill Valley, CA: Whole Systems Associates.

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C